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ABSTRACT

The monograph comprises the proceedings of a 1989 international conference on services to the deaf blind, including conference papers as well as reports from eight nations. Introductory material includes the text of the "Declaration of the Basic Needs of Deaf-Blind Persons" adopted at the conference, the conference program, and a list of participants. Papers have the following titles and authors: "The Use of Methods of Communication amongst the Deaf-Blind in Spain" (Daniel Alvarez); "Starting an Association" (Ove Bejsnap, Denmark); "My Life and My Finger Braille" (Satoshi Fukushima, Japan); "Open Employment" (Graham Hicks, Great Britain); "The Interpreter" (Katarina Johansson, Sweden); "Deaf-Blindness: An Emerging Culture?" (Roderick J. Macdonald, United States); "The Deaf-Blind Person and Advanced Technology" (Roderick J. Macdonald); "Polish Palm Alphabet" (Jozef Mendrun); "Deaf-Blindness in the United Kingdom" (Patrick Murphy); "The Importance of the International Newsletter" (Patrick Murphy); "The Importance of Retaining Your Language" (Sabina Santilli, Italy); "The Situation for Deaf-Blind People in New Zealand" (Janette Scahill); "Communication for Deaf-Blind in India" (Rajinder Singh Sethi); "On My Own Experience" (Sergei Sirotkin, Soviet Union); "Technology and the Deaf-Blind Population" (Robert J. Smithdas, United States); "My Personal Experience and Conditions for the Deaf-Blind in Colombia" (Yolanda de Rodriguez); "The Helen Keller Institute for the Deaf and the Deaf-Blind, Bombay" (Beroz N. Vacha). Additional reports summarize the situation for deaf-blind persons in Brazil, Canada, the Federal Republic of Germany, France, Italy, the Netherlands, Norway, and the Soviet Union. (DB)

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THE FOURTH HELEN KELLER WORLD CONFERENCE

ON SERVICES

TO DEAF-BLIND PERSONS

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September 28 – October 3 1989
Stockholm, Sweden

EC 300407

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Declaration of the Basic Needs of Deaf-blind Persons

The Fourth Helen Keller World Conference, which took place in Stockholm, Sweden, 28 September - 3 October 1989, adopts the following declaration, concerning the Basic Needs of Deaf-Blind Persons:

ARTICLE 1 Statistics indicate that deaf-blind persons exist in every country of the world. Every one of these countries should develop demographic data on its deaf-blind population for the planning of necessary services to assist these people to develop their fullest potential as citizens.

ARTICLE 2 Deaf-blindness is not blindness with the additional disability of deafness, nor is it deafness with the additional disability of blindness. It is a unique disability, requiring specialized services.

ARTICLE 3 Highly specialized training of professional workers is needed in order to take both deafness and blindness into account. Each country has the responsibility to train qualified professionals to effectively assess and evaluate the potential of its deaf-blind citizens. Where such expertise does not exist within the country, assistance should be sought from countries with established services to ensure that a basic level of quality service is available.

ARTICLE 4 Communication is the most formidable barrier faced by deaf-blind people. Communication is the key to learning, the acquisition of knowledge, and the access to others. Communication is imperative regardless of the potential level of achievement of the deaf-blind individual. This being the case, it is strongly urged that a high priority be placed on training deaf-blind individuals in effective communication methods. Native sign languages, manual alphabets, oral training, Braille and other technical aids and devices are all important avenues to effective communication that can be followed through the sense of touch. It is strongly urged, however, that deaf-blind individuals be offered training in several communication methods in order to provide the greatest flexibility in receptive and expressive communication.

ARTICLE 5 Every country of the world should provide specialized educational opportunities designed to meet the unique needs of deaf-blind people. Appropriate placement can often be found in programs designed for deaf children, blind children, deaf-blind children, or non-disabled children. However, each country should carefully evaluate which educational setting is most enabling for its deaf-blind children. Integral to the educational program for deaf-blind children should be a curriculum of basic self care and daily living skills.

ARTICLE 6 The loss of sight and hearing in itself is not a barrier to productivity in the workplace for deaf-blind people. Gainful employment in the least restrictive environment should be considered for every deaf-blind person with work potential. Appropriate counseling, training, job preparation, work placement and follow-up services are all important components of the rehabilitation process. Every country should develop these services to the fullest degree possible, with the deaf-blind person's active involvement in rehabilitative planning to the fullest degree feasible.

ARTICLE 7 Effective communication for deaf-blind people often requires the assistance of an interpreter. Interpreting services are the key to independence to deaf-blind people. Each country, therefore, should give priority attention to the professional training of interpreters. There are important differences between interpreting for deaf people and interpreting for deaf-blind people; these differences should be taken into account when developing interpreter training. Interpreting services are one of the most critically needed resources for deaf-blind people; they are an essential component of the overall service network.

ARTICLE 8 Alternative living opportunities are critically needed by deaf-blind adults. Supervised residential placement, supported apartment living, and fully independent housing are all viable living alternatives for deaf-blind adults, given appropriate preparation and training. Every effort should be made to find placement as close to a normal community setting as is feasible for the individual deaf-blind person. The deaf-blind person's individual preferences and capabilities should be a primary factor in determining the most appropriate placement.

ARTICLE 9 Opportunities for recreation and social interaction are as important and enjoyable to a deaf-blind person as to any member of the community. Because deaf-blind people themselves are often unable to reach out for these opportunities, society has the obligation to bring them to the deaf-blind person.

Social interaction with one's peers can have a very significant influence on a deaf-blind person's adjustment to and acceptance of the dual disability, thereby promoting a positive personal development.

ARTICLE 10 Public awareness of the needs, abilities, and achievements of deaf-blind people is of prime importance in securing governmental and community assistance to develop and maintain services needed by deaf-blind people. As a tool in promoting this awareness, and as a symbolic reminder of the achievements of the most famous deaf-blind person in history, it is suggested that the week of Helen Keller's birthday, June 27, be declared Helen Keller Deaf-Blind Awareness Week throughout the world.

The Fourth Helen Keller World Conference on Services to

Deaf-Blind Persons

PROGRAMME

THURSDAY 28 SEPTEMBER

15.00–18.00 Registration at Hotel Continental
20.00 Refreshments
20.30 Theatre, a Danish deaf-blind group

FRIDAY 29 SEPTEMBER

09.00–11.30 Opening speeches. Among those speaking will be Bengt Lindqvist, the Swedish minister for social affairs, and representatives of international and national organizations.
12.00–14.00 Lunch in the Town Hall.
15.00–16.00 Keynote Address, Dr Robert Smithdas, as former chairman of the WBU Committee on Deaf-Blindness (read by a deputy) "The International Newsletter" Patrick Murphy "Communication for deaf-blind in India" Rajinder Singh Sethi
16.00–16.30 Break
16.30–17.30 "Deaf-Blindness: An Emerging Culture" Roderick Macdonald

SATURDAY 30 SEPTEMBER

09.00–09.30 "Starting an association for the deaf-blind" Ove Bejsnap
09.30–10.00 "My life and my finger Braille" Satoshi Fukushima
10.00–10.30 "The Helen Keller Institute for the deaf and the deaf-blind, Bombay" Beroz Vacha

10.30–11.00 Break
11.00.11.30 "The deaf-blind of the Soviet Union" Sergei Sirotkin "The
11.30–12.00 Deaf-Blind person and advanced technology" Roderick Macdonald
12.00–14.00 Lunch
14.00–17.30 Technical aids and computers exhibited.
15.00–17.30 Parallell workshops
20.00 Cocktail party

SUNDAY 1 OCTOBER

09.00–09.30 "The use of methods of communication amongst the deaf-blind in Spain and how they work socially" Daniel Alvarez
09.30–10.00 "The interpreter, our best and most important aid for communication" Katarina Johansson
10.00–10.30 "Deaf-blindness in the United Kingdom" Patrick Murphy
10.30–11.00 Break
11.00–11.30 "The situation for deaf-blind people in New Zealand" Janette Scahill
11.30–12.00 "The manual alphabet in Poland" Jozef Mendrun
12.00–14.00 Lunch
14.00–14.30 "My personal experience and conditions for the deaf-blind in Colombia" Yolanda de Rodriguez
14.30–15.00 "Open employment for deaf-blind people" Graham Hicks
15.00–15.30 Break
15.30–16.00 "The importance of retaining your language when you have become deaf-blind" Sabina Santilli
16.00–17.30 Workshops
18.00–20.00 Dronninglund, the Nordic Staff Training Centrefor Deaf-Blind Services, holds a reception (see the invitation in your Conference folder)

MONDAY 2 OCTOBER

Free day. Visits to places connected with deaf-blindness will be arranged

19.00 Banquet
22.00–01.00 Dancing

TUESDAY 3 OCTOBER

09.00–10.00 Discussions
10.00–11.00 Closing

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The use of methods of communication amongst the deaf-blind in Spain and how they work socially.

Daniel Alvarez, Spain

Introduction

Since we began offering the first specific services for deaf-blind people through the Deaf-blind department of the Spanish National Organisation of the Blind (O.N.C.E.) communication has been a top priority for us.

It is a field in which we still have a lot to do. We are developing a basis to cover the most urgent needs of the group while we establish the required services.

We lack qualified professionals and therefore the training of teachers and rehabilitation experts in communication methods with the deaf-blind and the training of guide-interpreters constitute part of that basis.

In O.N.C.E.s educational and rehabilitation centres well trained professionals have the responsibility of improving and enlarging the communication level already achieved by our deaf-blind population.

In 1987 we studied the general situation of the 340 deaf-blind people registered up to that tiome. In a separate sheet we are providing a table that shows the percentages of use of the different communication means.

Accordning to our data, 41% of them use oral communication and this means that in most cases we are speaking of people with residual hearing (hearing impaired people, the so called hard of hearing people, etc). If the remaining hearing possibilties are very limited, they begin using sign language at the same time (17%).

Sign language is the method used by 26% of the deaf-blind and 5% use the manual. In this percentage we include those who only use this system.

We are also aware that a lot of those who use sign language also know and employ the manual, integrated into their signs, but up to now we have not been able to determine numbers in any precise way.

Communication among deaf-blind people themselves

Till a very short time ago, adult deaf-blind people only rarely got in touch among temselves. There were a few correspondence contacts, some people met in deaf associations and mostly, these contacts took place among the deaf-blind within O.N.C.E. in Madrid, but there were no special activities nor group meetings. Since the creation of the Deaf-blind Department, we have begun to promote meetings and the number of these has increased a lot and they already have a periodical character.

It was precisely during these meetings that we had the chance of realizing that to communicate among themselves they mostly use sign language with the help of the manual whenever necessary.

Through observation of a small group of 15 people who live in the Madrid area and meet rather regularly, we came to the following conclusions:

Only one of them is ignorant of sign language.

4 of them do not know the manual but they are learning it.

This group also allowed us to conclude through their characteristic that it is the congenitally deaf who became blind later in life who shows greater eagerness to get in touch among themselves. Those who still have some residual sight and/or hearing are more reluctant to communicate among themselves and they reject their being considered deaf-blind.

Present situation

Our department is promoting contacts among the young adult deaf-blind and we offer them means and encouragement to develop special activities and meetings an to enlarge the scope of their horizon in order to achieve a greater social involvement.

In order to achieve these aims we have taken the following steps:

Publication of the Internationsl Rewiew four times a year based on articles translated from the International Newsletter and with the addition of our own news and local subjets of interest.

Organization of leisure and cultural activities both at local and national level/tours, visits to museums, holiday week during the summer, etc.)

Support of the deaf-blind peoples own initiatives. In Madrid for example, foundation of the first club or association of the deaf- blind.

Cooperation with other organisations in order to make a better use of the existing means. One of the most useful achievements is the training of the first group of deaf-blind interpreters which was done with the help of the National Federation of the Deaf. In this way we made available to them the interpreters service of the regional government of Madrid.

We are planning the extension of this service also to the other Spanish regions. In this way, the possibilityof organising local and national meetings and activities will be increased.

These are only our first steps and we hope to succeed with many future projects in order to improve the general situation and the quality of life of our group. Rehabilitation is one of our most urgent needs.

O.N.C.E. has a residential Rehabilitation centre and many Rehabilitation Units for the blind but we do not have especially trained experts in rehabilitation and communication with the deaf-blind. This is one of our next projects.

While we take necessary steps, our search of means that facilitate and help communication goes on. We publish information brochures, we translate specialized materials, we go on with our research about technical aids and appliances as for example the A.V.K., a vibrotactile communication means which proved to be a very limited usefulness, etc.

Among other things we plan to do the following:

To edit various brochures about the problems and difficulties of the deaf-blind.

To research and select both among the different existing long distance communication devices (telephone for deaf-blind people) and face-to-face ones.

To promote the participation of family, friends, interpreters, volunteers, etc, as well as other agencies and bodies to complement our services and to increase the deaf-blind Spanish peoples involvement.

To go on promoting contacts with the deaf-blind and trying to increase their participation in the actions taken to solve their own problems.

This is the basis to achieve all the above mentioned aims. This is a long task and it requires to be patient, but we go on working and do look forward to every change we get, using all the available resources in order to create new and necessary services which we hope will be a reality in the non-distant future.

Table

Communication methods

Method	Absolute frequency rate	Percentage
Spoken language	140	41
Sign language	90	26
Spoken and sign language	17	5
Manual	16	5
Own family method	8	2
Sign language and lip reading	6	6
Sign language and writing	1	1
Other	9	3
None	41	12
No answer	12	4
Total	340	100%

Starting an association for the deaf-blind

Ove Bejsnap, Denmark

Dear friends,

I want to tell you a little about why we, the deaf-blind in Den- mark, have started our own society. But at first I want to tell you about myself. I was born deaf and have RP, also called Usher Syndrome. My parents were deaf-blind both of them.

About 25 years ago the deaf-blind started a committee within Danske döves landsforbund (the Danish association for the deaf) in close cooperation with Dansk Blindesamfund (Danish federation for the blind) and the Institute for the young and adult deaf. This committee functioned excellently and started many activities for the deaf-blind. The deaf-blind however had no closer communication with government authorities and were not on the list of the diffe- rent groups of handicapped. That is why the deaf-blind two years ago started their own association - foreningen danske dövblinde - FDDB.

The society holds an annual meeting and elects the board every two years. The board consists of 5 members, who are all deaf-blind and only the deaf-blind have the right to vote at the annual meeting, although passive members have the right to speak. FDDB has 8 different committees, and in these committees also passive members are included. The association has its own paid secretary.

We still work closely together with the associations for the blind and the deaf and with the association for parents of deaf-blind children.

Among the goals of FDDB are breaking the isolation of the deaf- blind and spreading information about deaf-blindness. We hav a lot of activities going; courses, holiday trips and theatre. We also work on improving the conditions of the deaf-blind by trying to find contact persons and interpreters, and by spreading information with the help of brochures and our theatre group.

The association has meant that it has become easier for the deaf-blind to make their voices heard and to influence society. We therefore think that it is important that the deaf-blind start asso- ciations of their own. I hope there will be associations for the deaf-blind in many countries in the future so that we can all work together to improve conditions for the deaf-blind all over the world.

My Life and my Finger Braille

Satoshi Fukushima, Japan

I was born on the Christmas day in 1962. I lost sight when I was 9 and at 18 I ceased to hear. I am 26 today, both deaf and blind.

I was a second grader in a high school for the blind when I became deaf. It was a most devastating experience to be virtually cut off from the rest of the world. I turned to books for solace. I wrote my diary or wrote letters to friends to comfort my soul.

Happily, however, around March 1981, that is, soon after I started my life as a deaf-blind, my mother hit on the idea of what I call my "finger braille." It was a most marvelous accident that led me out from almost total isolation. Let me give you an idea of what this mode of conversation is like.

In its barest outline, finger braille is a method of using the braille for conversation. The speaker using it lightly touches the index, the middle, and the ring fingers of both the hands of a deaf- blind in the same order in which he or she presses the keys of a Perkins Brailler. Each finger touched by the speaker, therefore, corresponds to the six dots of the braille.

Thus, when the conversation takes place with the speaker beside the person spoken to, the index finger of the deaf-blind's left hand will represent dot 1 of the braille. Similarly, the middle and the ring fingers of the hand will correspond to, respectively, dots 2 and 3. Also, the index, middle, and the ring fingers of the deaf-blind's right hand will stand for, respectively, dots 4, 5 and 6.

If the two face each other during the conversation, the index finger of the right hand of the deaf-blind will represent dot 1, and that of the left hand dot 4. In this instance, therefore, the left hand of the speaker will correspond to the right hand of the person spoken to and vice versa.

The touch is light, with fingers touching the back of the listener's fingers between the first joint and the bottom of the nail.

For the people who has already mastered reading braille on paper, they will find much less effort required to master reading finger braille than the effort required to learn how to read braille on paper for the first time. The reason for this might be that the braille reader's finger tip nerves are trained and has become sensitive.

Before proceeding further, however, it may be worthwhile to compare finger braille with the other modes of communication used by the deaf-blind.

So far the deaf-blind in Japan - and possibly elsewhere, too - have used three methods for communication. These are referred to as the finger spelling, sign language, and print-on palm approaches. Finger braille is speedier than both finger spelling and print-on-palm. Furthermore, finger braille makes deeper and more accurate communication possible than sign language. We will consider the advantages and disadvantages of the four modes now.

A comparison between the modes of communication prevalent in Japan among the deaf-blind

Print-on-palm

Advantages

1. Any one conversant with the letters of the KANA, it means the alphabet in Japanese language of communication can converse the method.

2. Only one hand is engaged in the conversation. With a little practice, messages may be communicated by "printing" them on the deaf-blind's back or the cheeks.

Disadvantages

1. The method is low in speed.

2. The order in which a letter is "printed" or the letter's shape tends to differ from speaker to speaker, complicating reading.

Finger spelling

Advantages

1. This method is faster in speed than print-on-palm.

2. A deaf-blind whose speech is impaired will find the method well-suited to his or her need.

3. Only one hand is engaged in conversation.

Disadvantages

1. Slower than finger braille.

2. Not many can use this method.

3. The method is not adapted to coding or abbreviations.

Sign language

Advantages

1. It is the fastest of all four approaches.

2. Especially reading messages the deaf-blind whose speech is impaired will find the method well-suited to their need.

3. The deaf or those adept in the sign language can use it with almost no difficulty.

Disadvantages

1. The messages that can be communicated in the method is not so accurate.

2. Touch reading in the method is difficult.

3. Those with no background in the sign language cannot use the method.

Finger braille

Advantages

1. It is faster than both print-on-palm or finger spelling and sometimes even faster than sign language.

2. It can be used for any level of conversation, however high.

3. The method is adapted to creation of codes or abbreviations. The existing abbreviations can be used as they are if the language of the conversation is English.

4. The method allows simultaneous communication with two deaf-blind if they place their hands one on top of another.

5. Persons conversant with the use of a Perkins brailler can start communicating in finger braille right away. Similarly, those who learn finger brailling will improve their efficiency in the use of a Perkins Brailler.

6. As it is, the method may not be of much help to the speech- impaired deaf-blind. However, the finger braille, combined with a computer keyboard adapted to brailling may led to the creation of a hand-held voice synthesizer.

Disadvantages

1. It is sometimes slower than the sign language.

2. It normally engages both the hands in conversation. One-hand finger brailling is possible though at he cost of speed.

3. It cannot easily substitute vocal communication by the speech- impaired deaf-blind.

4. Like those who can use finger spelling or sign language, finger braillers are limited in number.

Presumably, the above remarks hold outside Japan also. However, the rules of communication may differ in some respects, between Japan and the rest of the world. As for English braille, it is impossible to read English braille without any space between words because English is usually written with braille abbreviation. But in case of Japanese finger braille, it is written with syllabic characters and written without spacing and still it is easy to read.

But I think there is no reason why finger braille cannot be adapted to other languages as well, however. In fact, I have myself conversed with many who brailled English on my fingers. For example, in case of conversing by English braille, when the speaker is beside the listener, a thumb-to-thumb touch may serve as the space sign and substitute the space key of the Perkins brailler. Or we can use dot 4, as the space code, because in English this dot is usually used as a pre- marker. I do not know other languages like French or German very well, but in this way, I am sure you can adapt this finger braille method to other languages, too.

A measurement showed that a proficient speaker can communicate approximately 350 finger braille syllables a minutes without using the abbreviations we have created since the method evolved. The speed rises with the abbreviations. I would like to add here that no such abbreviation is normally used in Japanese braille.

Finger braille has made it possible for me to converse with a large number of persons. My friends who have volunteered to act as my interpreters use finger braille, too.

Next, let me select and present before you some of the most important instructions for the finger braille interpreters that I have listed in my "Finger Braille Manual for the Interpreters."

Use of the Finger Braille by interpreters

1. Try to constantly transmit some message or other. Do not allow communication to stop anywhere and yield way to silence. (An interpreter should imitate a radio running commentary on, say, a baseboll tournament.)

2. Use only direct speech when communicating someone else's utterances. Designate the respective speakers in company by a code for each. Use quotation marks to enclose the utterances. On principle, refrain from making summary.

3. In addition to communicating the speeches of the different speakers present, describe the environment. Do not leave out even the minutest details. Inform who are present in the room, that a glass just fell from the table, or that Miss Such-and-such is packing up to leave.

From this you will get an idea of the way my interpreters have been helping me ever since I entered university. I am a student of the Tokyo Metropolitan University where I am doing my Ph.D. in education at present. I not only attend lectures but actively participate in seminars. Quite often I lead the discussions and read reports. If necessary, I try my best to speak out during the lectures. If the others speak too fast, I request them to repeat. In other words, I feel as much at home in the discussions as any other participant.

In addition, since last year I have been teaching Japanese part-time in the high school for the blind where I studied before. There are ten students in each of my classes. I am accompanied by an interpreter who finger-brailles to me the questions asked by the students. I get to know in this way everything that happens in the class: funny events or if someone is talking to himself or is dozing! I am happy and so, too, are my students.

I am confident that I teach about as well as teachers with no physical handicaps. I would like to express my sincerest thanks to my interpreters for my success as a teacher.

Japan reportedly has around 20 000 deaf-blind. However, the facilities my country's national or regional governments provide them are by no means adequate. In most of the cases, The Japanese deaf- blind spend their lives confined within the four walls of their homes. For them there is no employment opportunity nor can they make friends outside.

I owe the chance I got of continuing my education in the university to a group of friends who have supported me all the way. I repeat that the

help I have had came from private sources and not from the government. The group arranges to train young men and women to act as my interpreters and raises funds to pay them.

This group is currently trying to establish a club for the deaf- blind. We are already meeting once a month to communicate and for recreational purposes. The club activities are yet to pick up - we have not yet been able to draw an appreciably large number of deaf-blind. However, in the years ahead, we plan to set up a fullfledged deaf-blind facility with job counselors and a pool of interpreters.

Japan has not advanced much in the education of the deaf-blind. In the university I am engaged in a study on teaching of language to the deaf-blind children. I am particularly interested in teaching these children how to read. I chose this as the topic for the thesis I wrote for my master's degree.

On the technological front, studies are under way all over the world to help the deaf-blind. Quite a few new devices have appeared that the deaf-blind find useful. A voice recognizer, a computer, and a compact paperless braille facility combined together can produce the kind of "hearing aid" using braille, that the deaf-blind need. I myself look forward to the day I will be able to use a device like this.

However, I must say that as a member of the deaf-blind community I find a friendly touch from someone who cares for us more reassuring than anything else. Nothing can brighten the lives of the deaf-blind more than men and women who reach them as friends. Those who share with us our smiles and tears help us best to feel life pervading the surrounding world in all its glory. They are the guiding flame we need on our way ahead.

It is important for our friends to attain skill in communicating with us. It is also important that technology should advance. But above everything else, the deaf-blind need manifestations of "love" in the world they inhabit.

My speech was translated from the original Japanese by my friends, Kalyan Dasgupta and Katsumi Tousu.

I must have taxed your patience, ladies and gentlemen, with my faltering speech. Thank you very much for allowing me to speak.

In conclusion, please let me read a small poem I have composed for this occasion. This poem was translated by my friend Kalyan Dasgupta.

My friend
Your magic touch
Sets me free
From captivity
Within a void
Where no light may reach
Nor a voice!

It leads my soul
To your own world
All aglow
With the love I long for.

Open employment for deaf-blind people

Graham Hicks, Great Britain

For over two and a half years now I have worked for Sense, the National Deaf-Blind and Rubella Association, as Development Officer for Technical and Welfare Services. When I first took up this new post my responsibilities included, amongst other things, the developing of Sense's braille transcription programme; the editing of the braille version of our newsletter; teaching communication, guiding and other skills; and assessing aids and equipment which might prove of use to some deaf-blind people. As time passed my knowledge and experience grew. I began go cover new areas, some of which today include advocating on deaf-blind issues, and working on the planning and development of services for deaf-blind people by local government and other local and national organisations.

But all this did not happen overnight. When I first started it was a very new experience with many things for both myself and my colleagues to learn. We all had to feel our way: finding out by trial and error, the best way to communicate, to process information and organise our working methods.

Communication is a particularly interesting subject - it is not just a question of finger-spelling or signing, but of learning to replace all the other parts of communication which I and other deaf-blind people may not be receiving, for instance tone of voice, facial expression and body language. Lack of these and other and sometimes more subtle parts of communication can lead to misunderstandings and other problems. It is therefore important that both deaf-blind people and their colleagues fully appreciate the need to be patient and find new methods to make themselves clearly understood.

In the course of those two and a half years many questions and problems have arisen, some of which many of you here today will have faced yourselves.

Perhaps the first questions were "what level and kind of support did I need? Would I need an intervenor, an interpreter or a secretary?" No

one was quite sure – it was new ground for us all. We tried the intervenor and the interpreter first, but neither was very successful. The intervenor wanted to make decisions on my behalf and saw the role as one of "looking after", but this was clearly not on. The interpreter only wanted to interpret, but this was no good either because more and more of the work was that of a secretary. It was finally decided to appoint a secretary which proved to be far more successful. But of course I still needed an interpreter for telephone calls and meetings, and we therefore trained her in these skills.

The next questions which we had to address were "how do I gain access to all the information which turns up on any busy office worker's desk? Do we expect another employee to copy it into braille or can modern technology provide a device which enables me to access such information independently? What are the advantages and disadvantages of these two alternatives?" Some have argued that it is cheaper to choose the first option because equipment is often too expensive. But copying is a time consuming business and presents a particularly passive task.

In fact I have found that being dependent on others in this way is not at all ideal or effective. Besides, what happens when this employee goes on holiday? Must I wait until their return to continue receiving information? It is not surprising then that I have found that the less I need to rely on others for support, the less the pressures on others and myself. It becomes more like an ordinary office job, where I am the decision maker and work provider. I find I need others for support less and less and I look to the future hopeful that modern technology, coupled with better access to the community, will continue to improve my independence.

But what of other deaf-blind people in Britain ? Very few of them have jobs of any description and even fewer are in open employment. There are many reasons for this including lack of awareness of the very existence of deaf-blind people and their potential for employment, and not forgetting the government's failure to pass anti-discriminatory laws. However, even within those organisations which advocate for the needs of deaf-blind people, there are few such persons employed and even fewer who carry any real responsibilities.

One reason is obviously lack of resources, especially money needed to pay for an extra employee to give support. But are some of us also guilty of underestimating the abilities of some deaf-blind people to work in a relatively independent way? When someone is asked "what jobs can a deaf-blind person do?" one either receives a blank stare or is given a list of half a dozen different tasks, most of which are simple or requiring little initiative. Some professionals will either say that while it would be nice to see a deaf-blind person doing a given job, it will be far more productive if done by a sighted- hearing person; or that a deaf-blind person can do any job except their own. All these examples are unfortunate and only serve to hamper still further the developments and progress of those who they strive so hard to help.

Deaf-blind people are often themselves unaware of their own potential because they have grown up in a sheltered world where most things are done for them. They are not used to making decisions - that kind of thing is best left to sighted-hearing people who obviously know best.

It is clear that real progress in this direction is going to have to mean a real change of attitude.

On the other hand there are those who will say that deaf-blind people, along with other disabled people, should run their own organisations without the participation of sighted-hearing people - a statement which I cannot pretend to support. What we need is equal opportunities for employment, both within our own organisations and the community. Segregation means divisions and "us and them", but we need integration with society, and that must mean unity!

The interpreter, our best and most important aid for communication

Katarina Johansson, Sweden

We who are deaf-blind constantly find ourselves in situations when we need the support of an interpreter, no matter how good we are at our methods of communication. If we have the help of a good and well-trained interpreter, the whole world lies open to us. We can do everything, and are not restricted any more by the need to see and hear.

Many deaf-blind people have shown that we can live a life that is rich and full of meaning, if there is an interpreter for us when we need one. Some of us have even won academic distinctions and some are prominent experts in the fields of culture and technology. But even for those of us who do not reach that far, the interpreter is necessary if we want to be in touch with the world.

When you interpret for a deaf-blind person you have to do much more than just interpret what is being said. You have to be good at many things. You have to know the method of communication that the deaf-blind person uses. The interpreter must be able to tell us, quickly and correctly, all that we can't see but which it is important for us to know. What is it like where we are? Who else is there? How do people react to the things we say and do? This is difficult, and it often means that the interpreter has to know a lot about the things that have to be described. If the interpreters are to do a good job, they must have a good education. But even the best interpreters have different personalities and interests. It is of course an advantage if we may choose the interpreter best suited for the job in question.

The possibilities for the deaf-blind to find interpreters are very different in different parts of the world. In some countries, society is responsible for providing interpreter service. In other countries the interpreter services are mainly voluntary, and the interpreters receive little or no pay. In some countries there is no interpreter service at all.

I will now tell you a little about the Swedish interpreter service for the deaf-blind and the deaf. For about eight years society has been responsible for supplying the interpreters that the deaf-blind and the

deaf need. Every county council has an interpreter centre with permanently employed interpreters. The centres also use interpreters who work on a free-lance basis. The county councils have to see to it that we have the interpreters we need in everyday life so that we are able to go shopping, visit the doctor, work in our associations and so on. When you study, the interpreter is paid for by the government. The associations of the deaf-blind and the deaf are also entitled to interpreters on public expense. The education of the interpreters is financed by the Ministry of Education and Cultural Affairs. The interpreters, who have to know sign language, study for two years. Our associations have influenced the education during the eight years that the interpreter service has existed. Our goal is that the deaf-blind and the deaf should have an interpreter whenever we need one.

During the past eight years, it has become much easier to find an interpreter, but there are still problems to solve. The deaf-blind and the deaf become more active all the time and the demand for interpreters is always greater than the supply. It is not unusual for us to find ourselves without interpreter. This has several causes. As I have said, the demand for interpreters is great. Another cause is that the interpreter service has not expanded, so that newly graduated interpreters cannot find employment at the centres. It is also a fact that interpreters are not highly paid. This means that not enough people want to become interpreters. Since there are so few trained interpreters we cannot always have the interpreter we want.

But in spite of all these difficulties, a well organized interpreter service is taking shape. We deaf-blind must continue to fight for our fundamental right of having an interpreter whenever we need one.

Deaf-Blindness: An Emerging Culture?

Roderick J. Macdonald, USA

INTRODUCTION

CULTURE - The totality of socially transmitted behavior patterns, arts, beliefs, institutions, and all other products of human work and thought typical of a population or community at a given time.

Recognition of the existence of a deaf culture has been an important factor in the recognition that deaf people are bona fide members of society. While no one would argue that it is a good thing to be deaf, recognition of the deaf culture encourages deaf people to accept their deafness as a fact of life, and to feel pride in their accomplishments and those of other deaf people.

But is there a separate culture of deaf-blind people? Could there be a separate community of deaf people with unique behavior patterns, skills, beliefs and other cultural traits, i.e. a unique culture of deaf-blind people? With this paper I hope to show that the answer is yes.

In preparing for this presentation, I sent a questionnaire to approximately fifty individuals with intimate knowledge of deaf-blind people; approximately half of these individuals were themselves deaf-blind. Of the approximately 15 people who replied in time for me to use their responses in this paper, all but one felt there was, in fact, a deaf-blind culture. Some replied with a hesitant yes; others with a surprised, but no less confident, affirmative; and several responded with such exuberant, even passionate, excitement that one wonders why this issue has not received much more attention.

The only respondent who felt that a culture of deaf-blind people did not exist in its own right, a sighted and hearing person who has provided volunteer services to deaf-blind people for many years, stated that her belief was based on the fact that, as a non-deaf-blind person, she felt completely comfortable and socially accepted by deaf-blind people, and that the atmosphere at gatherings of deaf-blind people was no different from that found at gatherings of other community groups.

In this paper we will trace the emergence of deaf-blind people through education, employment and social union into a modern community and culture. Deaf-blind people today are attaining new levels of individual achievement never thought possible only a few years ago. Of equal importance, deaf- blind people are achieving a culture within the greater society that deserves recognition and respect as unique and different.

EDUCATION

No one knows how many persons throughout history were both deaf and blind, for there seems to be virtually no record of a deaf-blind person until the eighteenth century. Perhaps the sole exception is found in the journal of John Winthrop, Governor of the Massachusetts Bay Colony, who wrote in 1637 of meeting an elderly deaf-blind woman in the town of Ipswich. It seems clear from his description, however, that the woman had good sight and hearing for much of her life, since she was able to receive receptive communication through the printing of block letters on her palm, and very likely retained understandable speech.

By the end of the eighteenth century, deaf-blind persons were known to the authorities in France, England, Scotland and Ireland, but it is unknown which deaf-blind person was the first to receive an effective education. Perhaps the first deaf-blind person to be taught a formal language was Victorine Morriseau (1789-1832) in Paris. Her education, however, seems to have been confined exclusively to religion. This was common to the education given many disabled people at the time.

The story of James Mitchell, the deaf-blind son of a Scottish minister born November 11, 1795, is related by the Scottish philosopher Dougald Stewart in "An account of a boy born blind and deaf." Mitchell had some sight, although both his blindness and deafness were congenital. He may have been the first deaf-blind person to communicate primarily through the use of signs.

It is generally accepted that the first deaf-blind person to benefit from a formal education was Laura Dewey Bridgman. Born in Hanover, New Hampshire (USA) on December 21, 1829. Laura lost her sight and

hearing, as well as her sense of taste and smell, through the ravages of a fever at the age of two years. She had learned to speak some words by this time, but soon lost this skill and never regained it again. In 1837, Laura was brought to the Perkins School for the Blind, where she was taught by Dr. Samuel Gridley Howe, the first Director of the Perkins School. Laura's success in becoming a well-educated and well-informed woman is one of the truly great landmarks in the history of education. She taught the world that deaf-blind people could learn.

Laura Bridgman died at the Perkins School on May 24, 1889. Before her death, she met the young Helen Keller, who was brought to Perkins by Anne Sullivan. It is interesting to note that Laura taught Anne Sullivan the American one-hand manual alphabet, so in a significant way Laura contributed to Helen Keller's education.

Four other deaf-blind students were admitted to the Perkins School during the 1840's, although none approached the academic achievements of Laura Bridgman.

It is a popular belief that most deaf-blind children are educated in schools for the blind. This is probably due to the pioneer work done by the Perkins School, and to the fact that the two best-known deaf-blind students in the 19th century, Laura Bridgman and Helen Keller, were both associated with Perkins. In fact, up to the turn of the century, the New York Institution for the Education of the Deaf educated as many deaf-blind students as did Perkins. The New York school educated eight deaf-blind students during the 19th century, the first being admitted as a deaf student in 1871 and losing his sight three years later.

By the end of the century, other schools were taking an active part in educating deaf-blind children. As the century came to a close, 16 deaf-blind children were still in school. They were in a total of 9 schools, mostly for deaf children.

There is little material available on the education of deaf-blind children in the early part of the twentieth century. In 1906, Willie Elizabeth Robin became the first girl to graduate from the Perkins School, and in 1938 Winthrop Chapman became the first boy to do so.

In the early 1930's, Perkins became the first school to have a separate department devoted to the education of deaf-blind children. Its initial head was Inis D. Hall, a trained teacher of the deaf, who arrived at Perkins in 1931. Shortly thereafter, six other American schools opened departments for the education of deaf-blind children.

Helen Adams Keller (1880-1968) is easily the best-known deaf- blind person of all time. In 1904, she was the first deaf-blind person to earn a university degree, when she graduated from Radcliffe College. Through her writings, public speaking and advocacy on behalf of blind and deaf-blind people, she was the single most important factor in the development of services for deaf-blind people. Ironically, Helen Keller did much more for blind people than for deaf-blind people.

By 1967, seven other deaf-blind Americans had graduated from American colleges and universities. In 1953, Robert Smithdas became the first to earn a Master's degree. Today, more than 100 deaf-blind Americans have earned college degrees, more than two dozen have earned Master's degrees, and approximately six have earned Doctorate degrees.

EMPLOYMENT

There is very little material available on the subject of the employment of deaf-blind persons. It is possible that Helen Keller was the first deaf-blind person who could support herself through gainful employment. However, Helen came from a well-to-do family, and much of her work was of a voluntary nature. During her career, she was employed by the Massachusetts Commission for the Blind, conducted a lecture tour, was in a vaudeville sketch, made a motion picture, did public relations work for the American Foundation for the Blind, and wrote extensively.

Thomas Stringer (1886-1945) entered the Perkins School in 1891 from a Pennsylvania almshouse. Shortly thereafter, a fund was started to support his education. His academic accomplishments were rather modest, but he was very good with his hands, and became a skilled craftsman in woodworking. After leaving Perkins in 1913, he went to

live with guardians in Pennsylvania, where he earned money making vegetable crates for local farmers, his future secure from this income and from the fund that had been started for him at Perkins.

Three other former Perkins students were able to support themselves through employment in sheltered workshops in the early part of the twentieth century. Cora Adelia Crocker, born in 1885, and Marion Rostron, born in 1889, were both successfully employed as chair caners by Woolson House, a sheltered workshop in Cambridge, Massachusetts. Chester H. Roberts, born in 1898, was employed in the broom shop operated by the Massachusetts Commission for the Blind, also in Cambridge.

Stephen Cartwright (1892–1938) was educated at Carnegie Tech as an engineer. At the age of 33, he lost his sight and hearing as the result of a cerebral hemorrhage caused by a skull fracture. He became a radio announcer after becoming deaf-blind.

Helen May Martin was educated at home before entering the Kansas School for the Deaf in her late teens. She was a talented pianist who learned to read scores in New York Point, and memorized them. She made many concern appearances throughout the Middle-Western part of the United States during the 1920's.

Just as the Perkins School has been recognized as the leader in educating deaf-blind children, the Industrial Home for the Blind, in Brooklyn, New York, has been a leader in the rehabilitation and employment of deaf-blind adults. The Industrial Home for the Blind first gave employment to a deaf-blind man in 1925, and by 1944 there were 13 deaf-blind persons employed at the IHB Industries. That year, IHB opened a special department to serve deaf-blind adults. This was the first such effort of a non-educational nature.

Today, there are deaf-blind people working in a wide variety of jobs, including computer specialists, accounting technicians, rehabilitation counselors and teachers.

ORGANIZATIONS OF DEAF-BLIND PEOPLE

In the late 1930's, Francis W. Bates, a blind man with a severe hearing loss, founded the American League for the Deaf-Blind. Initially, this organization was established as a service agency, providing personal services to deaf-blind Americans. However, the League enabled deaf-blind individuals to keep in touch with each other through correspondence. Shortly after Mr. Bates' death in 1948, the name of the League was changed to the American League of the Deaf-Blind, and it became a membership organization that is today known as the American Association of the Deaf-Blind.

In 1975, through the pioneer efforts of Doris M.J. Callahan, then the organization's President, and with financial and administrative support from the Helen Keller National Center for Deaf-Blind Youths and Adults and the Cleveland Society for the Blind, the first national Convention of deaf-blind persons was held in Ohio. With the exception of 1978, the AADB Convention has been held every year since, and has grown into the largest annual gathering of deaf-blind persons in the world. In 1988, 228 deaf-blind people and a total of 607 persons took part in the thirteenth such Convention, including 59 visitors from other countries. What is particularly noteworthy is that deaf-blind people themselves organize and manage these large Conventions. This self-determination has been made possible in large part through generous financial support from the American Foundation for the Blind.

Today, more than a dozen countries have organizations of deaf-blind people. Whether deaf-blind people should form and manage their own organizations, or belong to organizations for deaf people or for blind people, is still a controversial issue. However, it is clear that a strong movement exists for deaf-blind people to take a leadership role in managing their own affairs, a movement that is rapidly leading to a desire among deaf-blind individuals for self-determination, self-respect and self-fulfillment.

AN EMERGING CULTURE?

Environment plays a major role in determining one's culture and psychology. Deaf-blindness, especially when it is of early onset, alters a person's perceived environment in major and highly significant ways. These specific alterations in environment are shared by deaf-blind people and by no other group. Thus, certain behaviors, customs and ideas are unique to deaf-blind persons, and are central to our thesis that a separate culture of deaf-blind people does exist. This is not to suggest that deaf-blind people do not also share much with the greater "hearing-sighted" or deaf cultures.

In addition to the above factors that contribute to the existence of a deaf-blind culture, there is one major variable that prevents this culture from developing to its fullest. This is the isolation of deaf-blind people from each other. Jews, Blacks, Muslims, Japanese and other groups have cultures which are highly developed because members of these groups interact extensively and freely with each other. They often live near others of their kind, and sually share a common language that may or may not be known to the majority population. Until fairly recently, the idea of a unique culture of deaf-blind people would not have been tenable. Few deaf-blind adults had the opportunity to socialize regularly with their peers. Social interaction, for the most part, came through correspondence, an environment hardly suitable to the establishment of a unique culture. However, from this primitive beginning the seeds were sewn. Deaf-blind people were able, through correspondence, to freely express their ideas, needs, experiences and longings that later provided the basis for a unique cultural development.

One necessary ingredient for the existence and maintenance of any culture is the domestic union of two members of the affinity group - the custom we normally refer to as marriage. Marriage for most deaf-blind people to hearing or deaf spouses was rare prior to 1950, and marriage of two deaf-blind individuals was actively discouraged by society. Early in this century, when Alexander Graham Bell encouraged Helen Keller to consider the possibility of marriage should she find a man she could love, she responded by saying that she could not imagine any man wanting to marry her; she supposed it would be like marrying a

statue, since she had neither sight nor hearing. The bathos of this statement would be considered an insult by many deaf-blind people today. However, it was not until fairly recently that the marriage of two deaf-blind adults, and even parenthood, has received anything approaching acceptance within the community. Although there are at least 30 married deaf-blind couples in the United States today, with several new marriages occurring each year, there is still considerable prejudice against this on the part of relatives, professional workers and the general public.

Deaf-blind culture is at the present time in a relatively primitive, yet important, stage of development because its members do not usually have many opportunities for frequent social interaction with peers. Despite this obstacle, there are the following identified dimensions of a culture unique to the deaf-blind community:

TOUCH - Deaf-blind people must touch to make any kind of meaningful social contact. Touch is also required for communication. Thus, among those who are deaf-blind, extensive touching, both between the sexes and with the same sex, is acceptable and universal. Tactile contact that is commonplace among deaf-blind people would result in charges of sexual harassment or homosexuality among non-deaf-blind individuals. For example, what would the average sighted woman think if a deaf-blind man she did not know asked to feel her facial features? A similar request would not be considered unreasonable by a deaf-blind woman for whom touch is the only way of learning about one's environment. Of course, there are ample examples of deaf-blind men (and woman) who make a "good thing" of this need for and acceptance of touch by going beyond what is needed for communication, but the percentage of "dirty old men" in the deaf-blind community is probably no greater than in other cultures.

The widespread use of touch in the deaf-blind community has several implications. In the general population, there exists a wide range of difference in tolerance for touching. Most people in society, however, are extremely defensive bout any tactile contact with another person, especially in public. To these individuals, touching arouses feelings and impulses with which they feel uncomfortable. The net result is that these people reject contact with those who are deaf-blind. Thus,

deaf-blind people often face rejection from others through no fault of their own. It is due to the essential role of touch in their culture, and the general public's reaction to this.

GROUP COMMUNICATION - In all cultures except that of the deaf-blind, group conversations are common. This is not true for deaf-blind people, for whom all communication is generally one-to-one. This changes the basic nature of human interaction for deaf-blind people. For example, at a social gathering of hearing or deaf people, it is common for one erson to be talking, while a group of others listens. In this way, many individuals can share ideas and information in a manner that is not an option for deaf-blind people. As a result, the exchange of information is much lower and less economical for deaf-blind people. In addition, the whole social structure at social gatherings is different.

DEPENDENCE ON INTERPRETERS - Unlike members of any other culture, deaf-blind people are almost entirely dependent on interpreters to interact with the majority cultures and institutions of their society. This situation results in isolation, extensive costs, incomplete communication and, in many cases, a hostile-dependent relationship with the interpreter. This situation is further aggravated by the fact that the vast majority of skilled interpreters have been trained to work with deaf people, and have little or no preparation for or training in the unique communication needs of those who are both deaf and blind.

SOCIAL MORES IMPOSED BY DEAF-BLINDNESS - Deaf-blindness alters the framework for social interaction. For example, at a party, if one member of a deaf-blind pair wants to dance or talk with someone else, it can be awkward. Is the other member of the deaf-blind pair just left to sit in isolation? How do deaf-blind people mingle within groups? Is it a matter of bumping into one another and introducing oneself? These problems create an entire set of new and unique social rules. For example, when dining with deaf-blind people, it is considered appropriate for each individual to begin eating whenever food has been served, whereas in other cultures polite behavior dictates that everyone wait for the host or hostess to be served before eating. Additionally, it is considered acceptable for deaf-blind people to use their fingers

during meals, and as a result of this, deaf-blind people often prefer not to talk during meals, since their hands would also be needed for communication.

Similarly, when one wants to talk with a deaf-blind person who is reading Braille, the polite thing to do is to lightly touch the individual's hand, arm or shoulder, and to wait until the deaf-blind person can find an appropriate stopping place before lifting his or her hands from the Braille page.

When initiating a conversation with a deaf-blind person, it is only common courtesy to identify oneself, even if you are well known to the deaf-blind person. This is unnecessary for any other culture, since both sight and hearing permit ready identification of those we are communicating with. It is of critical social importance to deaf-blind people that they know immediately whom they are communicating with, since otherwise there is the danger of saying the wrong thing to the wrong person.

Proper etiquette also prevails when visiting the home of a deaf-blind person. When visiting the home of a sighted person, the norm is to look at, but not touch, furnishings and objects in the living room. Since touch is so important to deaf-blind people, it is only natural that guests should be free to touch objects in the living room. Many deaf-blind people would, in fact, be quite pleased if you showed an interest in their home by doing this. Exploring one's environment is considered appropriate behavior - but one should never, ever enter the bedroom or open closed doors or cupboards in a deaf-blind person's home without permission. Another word of caution here - one should never move objects in a deaf-blind person's home without that person's knowledge, for placement of belongings is, out of necessity, something the deaf-blind person must control in order to maintain order in the home.

GAMES - Integral to most cultures are games and sports, such as soccer, baseball, cricket, bull fighting and horse racing. The games and sports enjoyed by deaf-blind people tend to be more sedentary, such as board and card games. Tandem bicycle riding is quite popular, but

spectator sports are obviously inaccessible. However, many deaf-blind people do enjoy following sporting events in the abstract, such as the progress of one's local football team.

CLASS BARRIERS - Most cultures consist of huge numbers of people in close geographic proximity. In such cultures, class barriers are universal. These classes are caused by such variables as economic conditions, education, religion, social status or employment status. In a small culture of deaf-blind people, there are groupings based on such factors as English language competence, fluency in native sign language and method of communication. However, since the size of the total population is small, class distinctions, as seen in other cultures, are not nearly as significant in the deaf-blind culture.

REDUCED GENERAL KNOWLEDGE - Because deaf-blindness poses such a severe obstacle to education and communication, most deaf- blind people miss out on huge amounts of general information that is readily accessible to others. As a result, conversation in the deaf-blind culture often centers on news about one another and social interaction, and on basic issues such as food, weather, shopping, conveniences, and aids and devices of special use to deaf-blind people.

ECONOMICS - Since deaf-blindness makes earning money significantly more difficult, the deaf-blind culture is one of minimal material wealth. Social opportunities in the community generally must be organized with the financial or organizational assistance of community agencies, since deaf-blind people themselves are often unable to afford to pay for public entertainment options, especially if they must also pay for an interpreter to participate in these opportunities.

LANGUAGE - The issue of language and deaf-blindness is theoretically fascinating. Because deaf-blind individuals as a rule do not have an opportunity to interact as a group on a continuous basis, as deaf people have done for at least the past several centuries, they have not developed a separate tactile language. Instead, native sign languages and manual alphabets have been adapted for use by deaf- blind people.

There are interesting parallels to this. For example, for years, blind people tried to read raised print letters. That is, they tried to adapt to what sighted people used. In fact, sighted professionals condemned any attempt to develop a system especially for blind people. Similarly, for centuries, deaf people were forced to read lips and learn speech, thus adapting their communication to the needs of hearing people rather than the needs of deaf people. Today, many deaf people use sign language, a method of communication that is uniquely appropriate for a person who uses the eyes for receptive communication.

In my opinion, deaf-blind people are gradually adapting sign language and fingerspelling to meet their own unique communication needs. Subtle changes are beginning to appear. For example, a deaf-blind person who relies on fingerspelling as a primary communication method, and who is fluent in Braille, may often incorporate Braille contractions into the fingerspelling if the person with whom he or she is conversing is also familiar with Braille. In addition, many people who used sign language almost exclusively as deaf people will gradually use more and more fingerspelling once they have become totally blind for a period of time, and have come to feel comfortable reading Braille.

It is our view that, if deaf-blind people were allowed more opportunities to interact with each other on a continuous basis, they would gradually develop a tactile manual language ideally suited to their needs - that is, to touch. While this tactile language will have its roots in spoken and signed languages, it will gradually develop unique grammar and syntax typical of an independent language.

SUMMARY

Deaf-Blindness provides sociologists and others a unique opportunity to see how a culture develops from almost a total nonexistence into an emerging structure with the potential for further development. Variables such as communication, the opportunity for interaction, physical differences, economic level, education, modality of language, and dependency all enter into the nature of the unique culture deaf-blind people

have developed. With advances in technology, increased opportunities in education, employment and social interaction, and with the development of leadership skills among deaf-blind people, we predict an increasingly sophisticated, rich cultural development for the deaf-blind community.

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I would also like to acknowledge the valuable assistance provided by those who responded to my questionnaire.

The Deaf-Blind Person and Advanced Technology

Roderick J. Macdonald, USA

The most formidable problem faced by deaf-blind people is the problem of communication - communication with others, communication with information, communication with our environment. How well a deaf-blind person overcomes this problem is directly related to how well the deaf-blind person succeeds in whatever endeavor is attempted.

Until fairly recently, deaf-blind people have had to rely on others to facilitate communication. The assistance of another person, whom we usually refer to as our interpreter, has enabled many deaf-blind people to attain a high level of success in education, employment, recreation and other areas of daily life. The assistance of an interpreter is, and likely always will be, a very important part of a deaf-blind person's life.

The problem however, is that in order to succeed in our endeavors, we must depend on others, a very frustrating situation indeed. Imagine, for example, the frustration, and possible consequences, of having to miss an important examination at school because our interpreter became ill at the last minute. Imagine the disappointment a deaf-blind person would feel if unable to receive a prestigious award because our interpreter failed to show up due to automobile trouble. As important as our interpreters are, as much as we appreciate their assistance and support, deaf-blind people nonetheless dream of someday being able to do things themselves.

A century ago, through what was then modern technology, it was possible for a person to travel around the world in less than a year. This was an exciting feat never before thought possible - yet today, with advanced technology, the same feat can be done in a matter of hours. Who knows what might be possible a century from now? A century ago, television did not exist, but we may not have to wait another century before miniature cameras, either worn externally or implanted, might help a totally blind person "see". Similarly, with advances in cochlear implants, it might someday be possible for a profoundly deaf person to "hear" and understand speech.

I have been asked to share with you some thoughts on how advanced technology, especially computer technology, can greatly expand a deaf-blind persons access to information and to others. Advanced technology has been an important part of my daily life for the past twenty years, since I am employed as a computer systems analyst. However, it has only been in the past few years that computer technology has proliferated to the point where it is readily available to the average person, and even more recently to deaf-blind people.

When we talk about technology as it relates to deaf-blind people, we are invariably talking about technology that was designed and developed for something else, and has been adapted for application to the specific needs of deaf-blind people. For example, the typical alarm clock used by a deaf-blind person features a standard Braille alarm clock, developed for use by blind people, coupled with some sort of vibrator-signaling system that had previously been developed for use by deaf people. Neither the Braille alarm clock or the signaling system is technology designed for use by deaf-blind people, and quite often the technology must be adapted before it can be used by a deaf-blind person.

Even when a signaling system can recognize a standard source of auditory information, such as a door bell or telephone ring, and translate this information into a tactile format, it may not be immediately suitable for use by a deaf-blind person. For example, the "Silent Caller" can recognize information from four sources, such as telephone, fire alarm, door bell and alarm clock, and a receiver worn by the user will vibrate when a signal is received. The problem for a deaf-blind person is that the receiver unit indicates the source of the signal by illuminating one of four small lights imbedded in the receiver unit, and a totally blind person could not tell which light was on. Thus, even though the vibrating signal is readily perceived by the deaf-blind person, further adaptation of the equipment is necessary for it to be fully accessible.

This is not to say that all devices used by deaf-blind people were originally designed for somebody else. What I would like to emphasize, however, is that, given the generally high cost of developing technology and the relatively small size of the deaf-blind population, adapting

something that already exists presents the most practical approach to solving the technological needs of deaf-blind people in the vast majority of cases.

Take, for example, the problem of providing access to the telephone for deaf-blind people. The initial idea for solving this problem came after the development of telecommunication devices for the deaf (TDDs), which were originally modified teletype machines. These devices enabled deaf people to type on a typewriter keyboard, have the electronic signals translated into acoustic signals that were then transmitted over the telephone, and have the receiving unit at the other end of the telephone line translate the acoustic signals back into electronic signals, which then typed the message on a piece of paper. The earliest devices of this kind used by deaf-blind people borrowed some technology from blind people by using an embossing device that would write the messages in Braille on a strip of paper tape. The technology borrowed from the area of blindness had originally been developed to enable blind people to access computers. Although these Braille telephone devices were introduced less than twenty years ago, the technology was very primitive by today's standards - the devices were cumbersome, noisy, hard to read, broke down frequently and were almost impossible to move from place to place. At the time, it was state-of-the-art technology, but we have come a long, long way since then.

The problem of accessing the telephone still exists for deaf-blind people, even though several attempts have been made to design equpiment for specific use by deaf-blind people. Early versions of two such devices were displayed at the 1983 World Conference in Bahrain, devices now known as the DiaLogos from Finland and the TeleBraille from the United States. Each device took a different approach to solving the problem.

The DiaLogos, as it exists today, uses six pins which are raised and lowered to simulate the six dots of the Braille cell. The deaf-blind user places the first three fingers of each hand over appropriately spaced holes in order to feel the pins as they are raised and lowered. It takes a little practice to get used to this variation of the Braille cell, but it is quite simple to learn. The difficulty is that the user must use both hands to

read just one Braille cell at a time, and for anyone who has had access to paperless Braille displays with twenty or more characters displayed at once, this is a definite step backward. On the plus side, the DiaLogos has a built-in ink printer with typewriter keyboard, extensive memory, and user control of reading speed. It is also an ideal method for use by diabetics and others with limited sensitivity in the fingers.

The TeleBraille uses a standard TDD, attached by cable to a small box with a twenty-character Braille display. The TeleBraille is very user-friendly, and provides compatability with both ASCII code, used by computers, and Baudot code, used by most TDDs in the United States. It provided deaf-blind people with instant access to a vast network of over 10,000 telephones equipped with TDDs. On the down side, the TeleBraille has limited memory and is awkward to move around. Worst of all, the TeleBraille was designed to utilize a TDD already on the market for deaf people, and when the manufacturer of that device discontinued making it, the TeleBraille could no longer be manufactured without a complete redesign. Approximately 200 TeleBraille units are already in use, however, and a replacement TeleBraille, with improved features, is planned for some time next year.

Another approach to providing telephone access is to use a standard paperless Braille device, such as the VersaBraille, with modem or acoustic coupler. Many people in Europe use this configuration, sometimes with enhanced software or hardware to provide specific accessibility. The HASICOM system used in the United Kingdom is a good example of this type of system.

Another approach, and one I feel will be more widely used in the future, is to use a personal computer attached to both a paperless Braille display and a modem. The advantage of this type of system is that it provides far more than just telephone access, since the configuration also provides access to the computer itself, a whole new world opened to deaf-blind people.

In the case of DiaLogos, TeleBraille or Versabraille, the device providing the Braille output was the primary piece of equipment in use. In the case of a micro computer configured with a Braille display

and modem, the Braille display and modem become more peripherals; the computer itself is the source of power. For the first time, the equipment providing the accessibility is not the most exciting component – the real power comes from what is being accessed. While all components are important and necessary, it is the computer that is the heart of the vast opportunities opened to deaf-blind people.

In my work as a computer systems analyst, I need access to a vast amount of information. In addition, I must be able to generate a vast amount of information for use by others. A personal computer has proven to be the key to satisfying these needs.

First, I have access to the personal computer itself in both large-print and Braille. The large-print is provided by a display processor that displays the contents of the personal computer screen on a separate television screen at large, clear letters. Braille access is provided by a VersaBraille that also includes some special software designed to make the VersaBraille useful as a computer terminal screen. Thus I can read the personal computer's screen in either large-print or Braille, and I have just as much access to text on the screen as any sighted person would.

The same television monitor that enables me to read the personal computer screen also enables me to read all printed materials in large-print. A camera focuses on what I want to read, and pictures it on the screen in large, clear type.

The VersaBraille is also attached to a typewriter keyboard, so that co-workers can communicate freely with me by typing on the typewriter keyboard, with me reading what they type in Braille. This is very important to me because, as a supervisor, I do need to have frequent discussions with my staff. The VersaBraille and typewriter keyboard are also portable enough so that I can take this equipment to meetings and have a secretary act as interpreter by typing what is being discussed in the meeting.

I also need to be able to produce documents in both print and Braille. I have two printers attached to the personal computer, one for print and one for Braille. I can even use software to print in large-print if that is needed.

Since I also need access to our mainframe computer, as well as telephone access for conversational use, I have two modems attached to the personal computer. One of these modems provides high-speed access to our mainframe computer, while the other provides communication with TDDs in Baudot code, as well as access to computers at a slower communication rate.

Finally, I also have access to technology that allows me to convert printed documents into Braille. This is provided by an optical character reader which can "read" typed documents and copy the information into the personal computer, where I can use a word processing program or Braille conversion software to print it out on the Braille printer.

While all this equipment is quite impressive, it is the personal computer that brings it all together. Through the use of one personal computer and several peripheral devices attached to it, I can print documents in regular print, large-print or Braille, send or receive information from other computers, converse with other people over the telephone, read printed materials directly or have them copied into the computer for further processing, and communicate face-to-face with others. Incidentally, this speech was composed on a personal computer, corrections were made using a largeprint display, the Braille copy I am reading today was printed from a personal computer on a Braille printer, and the printed copy I sent to the organizers was printed from the personal computer on an ink printer. The system may not cook any dinner, but I could use it to call a restaurant and have my dinner delivered.

Some people feel that while advanced technology may solve problems for very gifted deaf-blind people, it is of little use to the average deaf-blind person. In fact however, this is not necessarily the case. Much of the development effort these days is being spent on developing a user-friendly interface for what is otherwise complicated equipment. The user of the equipment is not required to be a technical whiz. Few sighted people, for example, understand the technology that has provided us with television, but they are nonetheless able to turn the TV set on and enjoy their favorite program. With the development of the right kind of user interface, deaf-blind people, too, need not worry about the inner workings of the equipment; they need only master the interface that has, we hope, been designed with their needs in mind.

Many people would say that this is all fine and good, but advanced technology is very expensive, and deaf-blind people cannot afford it. This is a whole new subject deserving a whole new speech, and I am nearing the end of my time limit. However, one should not fault the development of technology simply because it is expensive. For one thing, costs generally go down once the development stage is over. For another, there are often ways of financing the equipment in a way that would not be a burden for deaf-blind people. In Scandinavia, for example, the Government usually provides needed equipment. In the United States this is not the case, but we were able to find a mechanism to finance over 200 TeleBraille units, at a total cost of over a million dollars.

It was also very expensive for many of us to attend this Conference, but here we are - a solution was possible.

Deaf-blind people have come a long way in recent years, but we still dream om someday being able to take charge of our own lives. Through the application of advanced technology, that "someday" may be just around the corner.

Polish palm alphabet

Jozef Mendrun, Poland

The Polish point palm alphabet (PPPA) was conceived and tested by a deaf-blind information scientist Grzegorz Kozlowski between 1986 and 1988. Its initial version was elaborated in 1986 and the final version was ready in 1988. It would be hard to describe it in detail, so I think it is not worthwhile to do it now. The Schematic diagram of "PPPA" is in front of you. I should only stress that "PPPA" is a **point** alphabet and its letters have been located on a palm with regard to the clusters of letters which occur most frequently in the Polish written language. Having considered just these two aspects we decided to elaborate the system of our own.

In every language there are som typical clusters of letters and particular clusters have different occurence in various languages. For instance , in the Polish language, the following clusters occur most frequently: "d – z", "p – r – z –y", "n – i – e". So, it proved important to situate the letters on palm within a relatively close distance from one another.

We decided that definite points on a palm should convey letters more adequately than lines for the two following reasons:
– It has been established that the perception of letters, represented by points, is easier.
– Printing of "PPPA" on special gloves is simpler that of the "line alphabet" or of the "mixed alphabet", i.e. the "point-and-line" one.

The alphabet of Grzegorz Kozlowski was taught on special fortnight gatherings of the deaf-blind persons, called by us rehabilitation courses.

80 deaf-blind individuals were trained: the basic means of communication in 50 cases (63 per cent) was the spoken language, in 25 (31 per cent) the sign language, and 5 persons (5 per cent) made use of individual, rudimentary techniques, known only to themselves and to their closest people.

The necessary conditions which a deaf-blind participant of the course had to fulfill to be trained in "PPPA" were:
- literacy (the notion of letters, words);
- ability to learn new skills.

Moreover, the following points were taken into consideration i qualifying a person for training in PPPA:

- inability to communicate by other methods than PPPA or difficulty in communicating by other methods;
- impending loss of ability to communicate by the method which has ben used until then;
- need for complementing the currently used method (methods) of communication with another, supplementary one.

The vast majority of the deaf-blind were willingly acquainting themselves with the new method and were able to master PPPA within a fortnight. On the average, after 4 - 6 twenty minutes' lessons a deaf-blind was in a position to locate letters on a palm, and after four twenty minutes' consolidating lessons more, was able to use PPPA to receive and convey information to others. The skill levels attained differed, of course, from person to person, and some students treated the PPPA method as a novelty. Together with the deaf-blind their guides, mostly relatives and friends, were trained.

In order to find out about current application of the PPPA method, mastered by the deaf-blind on the courses, a questionnaire was sent out this year in August.

The questionnaire was sent out to 78 deaf-blind persons. 46 of them answered.

The questionnaire contained the following questions:

1. Do you use the PPPA method?
2. If not, why?
3. If so, how many persons do you communicate with by this method?
4. Who are these people?
5. How often do you use PPPA?

29 persons (62 per cent of the respondents) answered that they did not use PPPA, and 17 per cent (38 per cent of the respondents) stated that they used it.

Out of the 29 persons not using PPPA – 18 (62 per cent) were brought up in the "spoken language culture", 10 (35 per cent) in the "sign language culture", and 1 person had his own method of communication. 13 people explained that they did not communicate by the means of PPPA because "there is no one to communicate with". 12 people said that they preferred other methods, 4 persons quoted both reasons.

Out of the 17 persons using PPPA, 11 (64 per cent) were brought up in the "spoken language culture", 3 (18 per cent) in the "sign language culture" and 3 persons (18 per cent) hade used individual communication techniques before they learnt PPPA.

11 persons stated that they communicated with one person only, 2 – with two, 2 – with three, 1 – with four, and 1 – with six persons.

12 persons communicated with the closest relative, 3 – with the people from outside the family, 2 persons – with both.

4 persons stat they used PPPA every day, 7 – once a week, 1 – once a month, 3 – more rarely than once a month, and 2 persons stated that it depended on circumstances, how often they could use the method; if they had someone to talk to, they did it quite often, but when the partner commanding PPPA had left, they did not use the method at all.

Conclusions

1. PPPA is a useful method, but its application is restricted;

2. The persons who are most inclined to use the method are the deaf-blind who have used rudimentary, individual communication techniques. This might be attributed to the fact that no other means of communication proved practicable for them.
3. PPPA is most rarely used by the deaf-blind brought up in the "sign language culture". This might be explained by the generally small reading and writing skills within that group of people;

4. PPPA is used mainly by the deaf-blind who have no other means of communication;

5. PPPA is a simple method, suitable for display on a special glove which facilitates communication even with the casually met people; and yet, the deaf-blind find it very hard to meet partners ready to talk to them in that way;

6. PPPA can be used as one of the available methods of communication and recognized as supplementary.

Deaf-Blindness in the United Kingdom

Patrick Murphy, Great Britain

When considering deaf-blindness we are talking about several categories of people with varying degrees of sight and hearing impairment, as well as those who are totally deaf-blind. I will therefore look briefly at these different categories.

Perhaps the largest category is formed by those who suffer from Usher's syndrome. Mary Guest, co-ordinator of the Usher Syndrome project at Sense (National Deaf-Blind and Rubella Association) is well informed on this subject. The project is in touch with about 450 families that include at least one member with Usher Syndrome. About 20 % of these people are under 20 years of age. A recent survey in the school population reported on 60 pupils currently in fulltime education in the United Kingdom. This total is low, and suggests a lack of awareness of such children in UK
schools. Note : no children were surveyed in Scottish schools, yet many young adults are calling on Sense in Scotland for services and should have been noticed at school. Sense is planning a rehabilitation programme for people with Usher Syndrome to be located permanently at Sense in the Midlands (Edgbaston, Birmingham). Two short rehabilitation courses have already been held involving four people with Usher Syndrome. Sense hopes to employ a fulltime worker at Sense in the Midlands later this year to run such courses. Manchester University's department of audiology and education of the deaf has shown interest in carrying out a study of children with Usher Syndrome in cooperation with Sense.

Issues:
1. There is an urgent need for earlier diagnosis.

2. There needs to be more thought given to the way in which professionals break the news of the diagnosis to families and individuals.

3. There is need for a more cohesive policy towards people with Usher Syndrome throughout their liveson the part of social services and rehabilitation services all over the UK.

4. Accurate information on Usher Syndrome should be readily available to families and individuals. Among those with Usher Syndrome, the increased awareness and development of rehabilitation courses signals an improvement in their conditions. There seems to be much unnecessary suffering because, when diagnosed, people have little or no idea of the nature of Usher Syndrome, and what is likely to happen to their sight in the future. The DES (Department of Education and Science) recently issued a policy document. This document acknowledged the existence of 800 deaf-blind children, and suggested ways in which local education authorities might meet their needs. This is the first official recognition of the educational needs of this group and it made some excellent recommendations, such as family advisory services, regional educational units and support for parents.

When considering the needs of deaf-blind adults, a document published nearly a year ago promises many improvements. This document, "Breaking Through", in highlighting deaf-blindness, has meant that an increasing number of people are being referred to the League. It is estimated that 11,000 people experience some degree of dual loss across the spectrum of deaf-blindness. The League recognises that communication, isolation, mobility and daily living skills are major areas of concern. Having recognised the need, the League is in process of developing its service staff, and workers are drawn from the deaf-blind world, the blind world and the deaf world. The League as a specialist agency aims to act as a provider of service, support and resources. Where possible we encourage statutory and voluntary agencies to accept their responsibilities of caring for the deafblind. "Breaking Through" has been instrumental in achieving this in some parts of the country. The League supports other agencies by assisting with, or hosting, courses, increasing awareness of the dual handicap and assisting deaf-blind individuals financially or in other ways. We also encourage the implementation of guide-help schemes, greater access to information, better training, developing opportunities for rehabiltation.

Major issues like housing, employment, education and rehabilitation will be advanced by cooperation BETWEEN agencies who pursue the same goals, Where there is UNITY AND A COMMON goal, sharing skills. knowledge and experience can ONLY lead to a uniform standard of care which will enrich the lives of those we serve, deaf-blind people.

There are laws to help the disabled, but unfortunately their implementation is often slow. Local and government officials ARE STRONGLY URGED to implement these laws: time is passing while officials deliberate: children are growing up and adults are growing older without the services and help that could make life tolerable. I might add that by procrastinating officials are storing up problems for future years, when because of neglect in earlier YEARS deaf-blind people encountere more difficulties and need more help. This help may involve residential caree at public expence, when with more foresight at the OUTSET children and adults could have been better equipped to cope with life as a deaf-blind person. There are other points to be borne in mind, some of which I have already mentioned:

1. More comprehensive implementation of the Diabled Persons Act 1986, and increased emphasis on the right of disabled school children to a full assessment prior to leaving school, and to provision and coordination of any necessary social services when they have left school.

2. The increasing elderly population which is expected to escalate over the next two decades or so will mean a significant rise in the number of elderly persons with hearing and sight loss. This rise will have an impact on resources, assessment techniques AND official policy.

In some ways the approach to deaf-blindness is more enlightened, but there appears to be plenty of room for improvement in the areas of awareness, attitude to those who are deaf-blind, and the quality (and quantity) of services that are provided.

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Mavis Sutter, RNIB

The Importance of the International Newsletter for the Deaf-Blind

Patrick Murphy, Great Britain

First, an explanation. I have received some enquiries asking what has happened to the newsletter. For twelve months spanning 1987-88 we received no funds from the United Nations. The League carried on publication but, since no funds arrived, felt that it could no longer be financially responsible for the Newsletter. Funds finally arrived in the summer of 1989, and we at once prepared the next newsletter, which you should have received by now.

Not so long ago few people ever left their village or town. They were unable to communicate with those at a distance except by undertaking long, slow journeys, or possibly by the use of visible signalling. Then came improvements in communication - telegraph, telephone, radio. Communication for the deaf-blind has been slower to develop. Awareness has been growing for a while now, and this awareness was accelerated by the International Year of Disabled People 1981. Now it is seen that the strength of the deaf-blind population lies in international cooperation between those who work with and for deaf-blind people.

The International Newsletter for the Deaf-blind began in India six (?) years ago, but was transferred to Britain, at Beroz Vacha's suggestion, as being a country that is closer to countries that have had more practice in improving the prospects of deaf-blind people. The Newsletter is important because it keeps those who are interested in touch with what is happening in other countries, both in deaf-blind welfare techniques and in the development of devices to improve the quality of life for deaf-blind people.

In the past it seems to have been considered sufficient that deaf-blind people were helpless and could not be taught some handicrafts, and that was about the extent of their "education". Perhaps this was because the authorities - and just about everyone else - assumed that deaf-blind people were helpless and could not be taught, so there was no point in trying. But we all know of deaf-blind people who, given the right help and guidance, we achieved much, even by the criteria of the

sighted-hearing world. These may be exceptional individuals, but if educated or rehabilitated with
understanding and skill most deaf-blind people can achieve a degree of independence. The authorities in all countries have a choice: to equip deaf-blind people to acquire a degree of independence, or to support them, perhaps for decades, in institutions, with the knowledge that one may have been responsible for wasted lives.

Until such time as each country awakens to the fact that it is neglecting a potentially useful section of the community - deaf-blind citizens - we continue to battle for our "place in the sun".

In past issues I have several times drawn readers' attention to the fact that we are short of material for the newsletter. There must be many readers who can tell us how the deaf-blind live in their own country, what if anything they have in the way of services, achievements of deaf-blind individuals, how you have solved a problem related to deaf-blindness; anything in fact to do with deaf-blindness which might help some other readers overcome their problems or encourage and inspire them to carry on.

One other point. We have received a few enquiries from people who want the Newsletter in large print. I am sorry, but funds will only permit us at present to print it in braille and ordinary print.

The importance of retaining your language when you have become deaf- blind

Sabina Santilli, Italy

The Harvard Psychologist Howard Gardner states : "Studies show that when someone suffers damage to a nervous system through a stroke or tumor, all abilities do not break down quite equally. If you have an injury to areas of the left hemisphere of the brain, you will lose your language ability almost entirely ...

Conversely, you can have lesions in your right hemisphere that leave language capacity intact but that seriously compromise spatial, musical, bodily-chinesthetic or interpersonal abilities."

In this paper I shall speak of those deaf-blind whose nervous system was left intact by the illness, no matter what their personal character, intelligence quotient, natural gifts and zest for life may be.

When, through an illness, the sensory organs of sight and hearing do not function more, but the concerned areas of the language in the brain are not affected, then the individual will retain his language ability quite well. And, if the deaf-blind generally do not speak clearly by voice, this depends mostly on lack of hearing control and on shortage of phonetic-ortoepic exercises.

However, the language does not consist merely in articulating words; it's much more a complex process of intellectual, psychological and relationship activities. More important still, those deaf-blind who had the chance to see and hear for some life-time, do consciously or unconsciously keep in their memory - I would say in their senses - the visual images and sounds they once perceived. I believe that even those of them become deaf-blind in their earliest infancy do retain, in their unconsciousness, at least the original schemes of the light, sound and word. This is well demonstrated by the easy way in which they do acquire an exact idea of the world around them as well as the speech - if properly led by the Educator to replace efficiently the lacking perception with all their remaining senses. Among these, besides Helen Keller, I should mention Charles Allen Crane in Canada, become

deaf-blind at only nine years of life; Giuseppina Manenti and Angelo Migliore in Italy, both deaf-blind since their two years of age. The former succeeded to get her Master's degree and acquired a perfect mastery in Italian language, although her oral speaking is hardly understandable to persons not accustomed to her voice. The latter, as profoundly deaf, learned a good oral speech through his sensitive, very active hands. Some interesting observations on experiences of a deaf-blind since his pre-school age, are made with realism and deep psychological competence by the Russian deaf-blind Olga I. Skorokhodova in her book: "How I perceive, imagine and understand the world around me." I would recommend it for reference.

Those who lost their sight and hearing during the school years, of course had by then already acquired a more precise knowledge and awareness of the physical and psychological realities as well as a good language ability. Then, useless to say that their education and training will be much easier and their intellectual development more rapid. However, here I do not intend to speak on the subject of education, rather more especially on the role of the language in the lives of deaf-blind people.

First of all, as generally known, the words mot only can represent in to our minds ideas, abstract concepts, etc., but have also the power to rouse sensations experienced in the past. As you read or pronounce silently a word, it will remind you not simply of the image of the object in its shape and colour, but also a voice, an accent or tone resounding in the three dimensions of the space, in the same light anywhere you may have heard it once. One can remember the episode of Helen Keller with the word "water" for instance. Something happened to myself. While studying German, as I tried to pronounce words according the phonetic explanations, I had the feeling of a young woman's clear voice, in a bright sky light. Then surprisingly, I discovered I had heard to speak German in my childhood - distinctly by that slim, energetic Austrian lady once dwelling at my sister's Antonietta. She could speak Italian very little, indeed, as my brother-in-law assured me then. (She migrated to Argentina with her family 35 or 37 years before, and I heard nothing more of her).

In this way the words, stirring up sounds in our gently zooming ears, do evoke many complex, vivid realities in our minds. Even reading poetry or songs, can rouse musical sensations of some arias or melodies. This explains why many deaf-blind are so fond of reading, especially on voyages, history, geography and every kind of literature books.

On the other hand, it is interesting to observe how a deaf dumb since birth or so become blind in later youth or adult life, tends to refer much more to visual representations, gestures and actions in speaking, than to spell complete sentences. A congenitally blind become deaf in later in life, on the contrary, has a richer language in speaking, but does refer less to visual images.

However, there are some deaf-blind who do not like much to read; they probably have no great imaginative ability or, may be, they have not many elements for representations of everything seen or heard. Nonetheless, some of these are quite eager to learn and do like to get a lot of information through living contacts and warm conversation with people of their entourage.

At this point, I would stress the importance of urging deaf-blind children to perceive and learn speech as much as they can and how much their natural aptitudes do allow, no matter at what age they have lost their hearing. And, associated to the language teaching, continous contacts with everything and intense experience in every kind of physical and mental activities will nurture the learning and be more efficiently constructive than arid forms of words alone, which would mean nothing to the child.

Moreover, it is of great importance for deaf-blind adults to cultivate at most their language ability, with phonetic-ortoepic training, and getting as much information as possible, for their cultural growth and to keep constantly alive their sense of presence of the reality around them - I would say, to have a clear vision of everything in their environments for an immediate understanding of circumstances through lightest clues, thereby ensuring their maximum independence in mobility, work and social relationships. For richest information the Braille is obviously indispensable, as precious are also the technical aids for distance communication. But equally indispensable will be a simple, clear and easy

manual alphabet for direct conversation with everyone around the deaf-blind. Even the information about smallest things happening in his environment, will give to the deaf-blind person a more exact awareness of everything and everyone around him and, above all, an immediate more intelligent understanding of his loved ones and a fullest participation to the lives of others.

The situation for deaf-blind people in New Zealand

Janette Scahill, New Zealand

We in New Zealand are pleased to report that we now have our own Society for people who have the double handicap of sight and hearing impairment. This Society was registered only last December, and its National Executive Committee is now organized, with representatives from the two main islands.

Because our small population, some three and a quarter million plus, we do not have a great number of people with severe loss of hearing and sight, but there are some three hundred with a degree of both. Because of this we refer to our members as VISION and HEARING IMPAIRED, or in short V.H.I., and not DEAF-BLIND.

The Royal New Zealand Foundation For The Blind is at present celebrating its centenial, as it was 100 years ago that the Jubilee Institute for the Blind, as it was formerly known, was established. When I started school there in early 1940s it was known as The New Zealand Institute For the Blind, which it changed to in 1926. In 1955 it became the N.Z. Foundation for the blind, and by act of Parliament in 1972 it gained its present title. Recently I attended the opening ceremony of these celebrations, and as we finished that afternoon I passed the remark "the vision impaired have had the first hundred years, V.H.I. are now starting theirs."

The first real step toward special education for our really Deaf- Blind children began in 1967, when a unit for these youngsters, some having other disabilities as well, was established with our school for the blind in South Auckland, known as HOMAI COLLEGE. It still operates for this special purpose, and has a present role of 12, aged between 3 and 18 years. We also provide education for our indigenous Maori people, and those who have settled in New Zealand from the Polynesian Islands of the South Pacific.

It was in 1985 that work began more fully for people with this double handicap, not just the severely effected, but all those whose sight and hearing is impaired.

Previously our more severely affected people had found employment in the Foundation's workshops, mostly working as basket makers, or doing rope work, etc. But these are not protected industries in our country, and therefore the blind, unless they work independantly, have had to find other occupations. However quite a number are without work. Fortunately though most blind people in N.Z. receive pensions, and certainly those in this category do.

So it was in 1985 the Foundation employed Tom Rogerson, retired Principal of our School for the blind, as Special Projects Officer, and one of his main duties was to improve the services for our V.H.I. people. A committee was formed, andwork began. Finding names and addresses to collate a list of members had to be accomplished. Then organising our first National conference, which washeld in early 1987. Through discussion groups at this, goals and objectives were set. It was there that the proposal was made for the "Deaf-Blind" of N.Z. to be known as V.H.I., one reason being that which I have already mentioned, and it was also felt that V.H.I. was a less harsh term. So it has been adopted. It was also at this conference that possible Cell Groups were discussed, these to be set up in any place where there were sufficient V.H.I., and someone from this group was prepared to be its leader. Six of these now exist, and they meet on a friendly, rather than a formal basis, supporting each other,exchanging ideas, discussing problems to be overcome if possible, and inviting speakers on various subjects of common interest. Now, after the Society's formation, they play a very important role, reporting to us and we, of the Society's Executive Committee, to them.

It is an excellent way to keep in touch with our members, spreading news and developments.

A second National Conference was held last year, and it was there that a proposed Constitution for our Society was put forward, and the final details for its setting up.

Initial goals for the Society areas follows:

1. Getting our intervenor programme in to action.

2. Improving availability of technical aids, and establishing a fund-raising scheme to assist those in need.

3. Developing optional living programmes: independent living units, etc.

4. Improving communication skills in what ever way we can, including on a person to person basis, group gatherings, telephone systems, and news services.

5. Encouraging and helping more Cell Groups so we can have better contact with V.H.I. people in more areas.

6. Opening up more employment opportunities.

Whatever else arises of importance in the future we hope to be able to work on together, not only here in New Zealand, but also with our neighbouring country of Australia and the Pacific Islands. As I have been asked to specificly work with these people by the WBU'S Regional President, David Blyth of Australia, and also in my present capacity as President of the N.Z. Society for V.H.I., bettering all aspects of lifestyle for our people of this part of the Asia/Pacific Region is very important for me.

Thank you for the thrilling opportunity of being here at this time, and having the privilege of telling a little of New Zealand's growth in this challenging work, we are so delighted to be with you all.

Communication for deaf-blind in India
- what methods there are, how they are taught

Rajinder Singh Sethi, India

I wish to speak to you on the situation of the adult deaf-blind in India and leave the situation of the deaf-blind children in India to Mrs Vacha to discuss in the second half of this paper.

There are no surveys carried on to ascertain the number of deaf-blind population in India. I personally know of six deaf-blind adults, one female and five males ranging from age forty to sixty.

A hearing test carried on a couple of years ago by the Ali Yavar Jung National Institute of Hearing Handicapped on the inmates of the rehabilitation workshop for the blind in Bombay found that some of the blind suffer from hearing impairment.

Now coming to the theme of the Conference, Communication at all levels: For an adult deaf-blind communication means better living and more independence. He needs to communicate with his family, friends and his employer. He also has to deal with the other people in the community for his day-to-day living.

With this dual sensory impairment it is natural that he has to have a few trusted members of his family and friends who can act as his eyes end ears, so that he can live better in the environment. He has also to motivate the public at large to help him to move around freely.

The five deaf-blind males including myself are totally blind and going progressively deaf. We use a body hearing aid and can communicate on a one-to-one basis. Three of us were born blind and started losing hearing during adolescence. The other two lost their sight in adolescence and are going progressively deaf.

My life experience will help you undestand how difficult it is to function with dual sensory impairment and yet to achieve and adjust to the best of my abilities. I have recently submitted a doctoral thesis on education. The title of my thesis is "Socio-Educational Problems of the

Employed Blind in Bombay". This has been possible with the aid of National fellowship from the government.

You will ask how could I cope up with the field work, reading and writing, so necessary for preparing for a doctoral degree. I could not have done it without the assistance of volunteers. Since my subjects were employed blind - they too my friends - cooperated with me.

The readers have to read into my hearing aid and hence the environment should be free from noise. Also they have to read louder, clearer and slower. Not all readers possess these qualities.

I am grateful to my readers for not only reading to me but also giving valuable company to me, since my social life has been very limited due to my hearing impairment. I have also been contributing regularly to International Newsletter for the deaf-blind and Blind Welfare, due to vorations reading in Braille and with the help of voluntary readers. This way I pass my time and also derive mental satisfaction.

I rarely attend parties and therefore have kept few friends who can talk to me on a one-to-one basis. I also talk to my friends on the telephone. For a deaf-blind person quality friendship matters more than quantity friendship. I stay in a large family. When there is a party or a social gathering one will find me in my room reading, glueing my ears to the radio or talking on the telephone. Not that I dislike parties but I get lost on such an occasion.

I am trying to learn tactile communication like printing on the palm, finger spelling from the teachers of The Helen Keller Institute for the Deaf and deaf-blind, Bombay, but so far have not made much progress. In this connection I cannot but appreciate Mrs. Vacha for her help and guidance.

Before I conclude I would like to make a few suggestions:

1. It has been found that some born blind or losing sight early tend to suffer from hearing impairment later on. A hearing screening test should be carried on, on such children.

2. Telephone amplifiers should be provided by the telephone authorities at no cost for the hearing impaired.

3. Loop System should be installed at well-known cinema houses, conference centres, theatres and concert halls, so that the hearing impaired can visit and enjoy the events.

On my own experience of communication

Sergei Sirotkin, USSR

My name is Sergei Sirotkin. I was born with weak sight and being severely hard of hearing. I lost the sight of one eye when I was one year and two months old. I lost the sight of my other eye when I was 6. Before having become absolutely blind I did not use my residual hearing at all. So I had no normal speech. I used simple signs for communication. As I was told by my kinsfolk, I had some kind of prattle, I mean some separate words, such as "mum" and "dad". But I don't remember it myself. I had no speech memory, I had that time before becoming completely blind.

But I preserved some visual impressions and even visual images of the time. Many of them are vague now for I had them long ago. I do remember that things had different colours and seemed smaller at some distance. These visual impressions and even images helped me very much during my education just to form and develop some concepts of different objects, including ones I had seen long ago.

For instance I formed the idea of white colour on the basis of my visual memory of snow and milk, which I associated surely with the word "white." I associated the idea of red colour with the word "red", having remembered the colour of Pioneer's red tie and the same colour of the blood. The idea of green colour I associated with my recollections of green medicine (a nurse in our kindergarten had many spots on her hands). I associated green colour also with green grass. Before becoming blind I had stayed in a kindergarten for the deaf. I hade been staying there some time even after losing my vision. At that time my special education as a deaf-blind person began. My education was directed by a famous soviet teacher of the deaf-blind, professor I. A. Sokolyansky. I was taught independence, speech and civilised conduct according to his methods.

According to Sokoyansky's methodology I was taught not only by class teachers, but also by my mother - both at kindergarten and at home, and even afterwards at school for the blind. When I became absolutely

blind my mother had left her job and became my personal educator. She used to show me different objects, and explain me what it was. I couldn't understand everything at once, but I liked it. I always liked to learn new things.

The teachers of deaf children, R.A. Mareeva and G. V. Vasina and my mother paid great attention to the development of my speech. They used simple signs and manual alphabet. They taught me Braille also.

When they taught me to pronounce speech sounds I was demanded to use only oral speech for communication. However my speech was indistinct, and only my mother and my teachers were able to understand it.

Thanks to my mother I realized that I could hear something: she always talked to me in a loud voice, accompanying her speech with signs and finger spelling. She did so, although the teachers and the physicians did not allow me to speak (oral speech). In this way she unconsciously taught me to recognise some words by ear. Afterwards when I became a teenager, I was able to understand my mother's oral speech. I attempted to communicate in such a way with other sighted – hearing persons, but we could hardly understand each other. So my main way of communication with a sighted – hearing person is still manual alphabet, and Braille.

An outstanding part in my language development played O. I. Skorochodova, a famous Russian scientist and writer, who herself was educated by professor Sokolyansky. I made the acquaintance with her during my stay in the kindergarten shortly after my misfortune. I became attached to her as I saw she was the same deaf-blind person, as I was myself. We became friends. First I could tell her little but she cared for me very much. She communicated with me only through manual alphabet.

When I had been taught Braille, we became pen friends also. I felt the necessity to be in correspondence with her, and that was a powerful stimulus for my word speech development. As my teachers, Olga Skorochodova, controlled my literacy correcting my mistakes and often demanding to rewrite the text without mistakes ...

My contacts with friends influenced my development greatly. My recollections of the kindergarten period are most kind and fair. Fortunately deaf children there were considerate and benevolent towards me when I had already become deaf-blind. I possessed equal rights being a participant of their games, and often I became the "ring leader". I used sign language for communication with my deaf friends. The experience of my sign communication was very useful for me later, at Zagorsk school for deaf-blind children.

After kindergarten I was transferred to Moscow school for the blind for further education, where I was assisted by G. V. Vasina, the same teacher of deaf children. At that school I was taught also individually, according to a special programme for the deaf-blind. I had not many contacts with my blind class mates, for they could not understand my poor speech and I was not able to realise even their loud speech. A few blind girls and boys learnt manual alphabet from my mother and so they were able to communicate with me sometimes. But at that time I felt a lack of words to communicate with them. I compensated the lack of communication with my classmates reading books for children and also communicating with adults, mainly with my mother, my teacher and Olga Skorochdova. That also helped my speech development.

After the foundation of Zagorsk school for the deaf-blind I was transferred there as one of the first students. At Zagorsk school I was educated in accordance with the curriculum of our secondary school. There I was amid deaf-blind children of the same age. I was able to communicate with them as well through the manual alphabet and through Braille. I preferred to deal with sign-speaking deaf-blind children. I had among them my good friends and my first love also ...

That deaf-blind children taught me more developed sign language, one of the deaf adults. So I have both my sign language and my speech being equally developed. That enabled me to communicate with people in both speech environments. Thanks to this fact I was able to know the life and the needs of sign - speaking deaf-blind very well for those needs are usually known to sighted-hearing persons and to those deaf-blind who become deaf later. In this way I understood that the deaf-blind are very different and have very different needs and

problems. This is why deaf-blind people need individual approach. This knowledge now helps me in my work as the chief of the section for social rehabilitation of the deaf-blind
persons.

My knowledge of life of the deaf-blind is not only theoretical knowledge.

When I studied at the faculty of psychology of Moscow University I had many contacts with scientists of different specialists. When I stayed at Zagorsk school I learnt to use ordinary type-writer, and this enabled me to be in correspondence with many sighted and hearing persons who did not know manual alphabet or Braille. I was also enabled to type my research articles for the scientists and for publication. Besides, We four deaf-blind students used a collective device for communication - Tellatouch. We were able to hold our seminars, to communicate with our teachers, with sighted - hearing students and with different visitors.

At the university I found my big friend and like-minded person. I mean Elvira Shakenova, D. Ph. and a member of the Union of Soviet writers. Three years later she became my wife and my co-worker. We made a kind of creative duet being mediators between the deaf-blind and sighted - hearing persons. With my help Elvira Shakenova opened the deep strata of the world of the deaf-blind, and she opens for me the world of the sighted - hearing. Besides, my wife continued my mother's practice to speak with me orally. Good hearing aids were bought for me and now I can talk to my wife orally, even using an ordinary telephone. This hearing aid helped me to correct my oral speech, it became much more distinct. Yet I still can hear very few people - only my wife, my mother and those who have good distinct articulation.

The experience of communication with the deaf-blind as well as with the sighted - hearing determined considerably the choice of my work.

Long before my work at the section for social rehabilitation of the deaf-blind, I felt the gravity of complicated problems of social work with deaf-blind people. My friendship with the sign-speaking deaf-blind

prevented me from feeling any superiority towards them (as often do feel persons who became deaf later).

The Judgements about deaf-blind people as if being "defective" or "primitive" fill me with indignation. I can't respect those who believe they are more intelligent and better than many other deaf-blind people only because of favourable conditions of their own developments.

My own attitude to deaf-blind people is different. We must regard the deaf-blind as persons equal to ourselves and needing our help, because they were deprived of better education due to their conditions, both physiological and social. We must help them both directly in practice and through research work, helping to solve their problems which even scientists of standing reputation are sometimes unable to solve. There are a lot of fine words about immediate unlimited development of all the deaf-blind, but such words are pointless and idle. We must know real problems of deaf-blind people and be able to solve them. This is why my wife and I chose our profession: research and practical work to help the deaf-blind.

Technology and the Deaf-Blind populations

Robert J. Smithdas, USA

There is no question that the dual disability of deafness and blindness is one of the severest handicaps known to mankind, and that people who lose both sight and hearing face unique problems that make it difficult for them to function independently. Sight and hearing are the primary channels through which we acquire information and knowledge of the world we live in; and when these two senses are damaged or absent, there are serious problems of communication, orientation and mobility that limit the deaf-blind individual's sense of independence.

To overcome such problems, it is necessary to establish ways and means of substituting for the loss of sight and hearing by using other methods to provide the deaf-blind indvidual with access to information. It has only been during the past two decades that we have been able to make real progress in overcoming these problems by using available technologies to improve existing conditions. We now have special signalling systems that alert a deaf-blind person when the doorbell or telephone rings, devices that make it possible to communicate by using the telephone, and computers, braille printers, and braille displays, or large-print displays, that may eventually open up whole a new environment for employment and leisure-time activities. This is a time to be optimistic and to assume that we have barely tapped the possibilities.

Modern technology can provide solutions to many of the problems that confront deaf-blind people in today's society. But we need to recognize the fact that the special products of technology are often beyond the financial means of most deaf-blind individuals, and that we must find a means for making them avaiable to those who can use them. We need to find and evaluate existing products that can be modified for use by the deaf-blind at minimum cost. And we should recognize the importance of keeping all deaf-blind people informed of all technical advances that may be of interest to them, and the sources of supply from which they can obtain aids and devices that can be useful to them in achieving a measure of independence at home and at work.

It is very important that deaf-blind people be kept informed of technological developments. there is an urgent need to centralize information about aids and devices that may be of use to the deaf- blind population, including sources and products, detailed descriptions and prices. There should be a universal catalogue describing items that are currently available that should be updated annually. Agencies engaged in training and rehabilitation of the deaf-blind should provide samples of such items and be able to arrange for their clients to obtain needed equipment, perhaps at government expense. And schools that provide education for deaf-blind children should be able to teach their students how to use such equipment. Deaf-blind people should be given the opportunity for hands-on experience with aids and devices so that each individual can decide and choose which ones will be of most benefit in alleviating the problems they face.

There is no doubt that modern technology is providing many deaf-blind individuals with a greater sense of personal security and self-confidence today, and that it has opened new areas of potential for them. But we must not assume that technology will ever be able to substitute for the natural spontaneous senses of sight and hearing, or that it can solve all the unique problems related to the dual disability of deafness and blindness.

What aids and devices are best for deaf-blind people ? There is no easy answer to this question because each individual differs from others in capacities, abilities and needs. What may be helpful for one person may not be suitable for another person. The best judge of whether a device can be useful and beneficial is the deaf-blind individual; he must evaluate it in terms of his personal living needs.

My personal experience and conditions for the deaf-blind in Colombia

Yolanda de Rodriguez, Colombia

I would like to present a very special greeting to the deaf-blind representatives from the various countries and professionals gathered in this beautiful city of Stockholm on occasion of the Fourth Helen Keller World conference. I would also like to express my appreciation to Mr Stig Ohlson and his associates for inviting me to speak about my experience as a deaf-blind and paraplegic person, and how I have been able to rehabilitate practically by myself in a country without many resources, and what we are doing on behalf of the deaf-blind.

I am from Colombia, a country located on the North-Western part of South Amerika, with coasts on both the Atlantic and Pacific Oceans. One-third of our territory is mountainous and the rest consists of plateaus, fertile valleys and the Amazonic zone. We have a Democratic system of government and, like most of Latin America, we are one of the many developing countries.

It is for this reason that the conditions of the handicapped people become difficult due to lack of appropriate technology and human resources. There are no Institutions for the deaf-blind and 17 years ago, when my accident occurred, there was not even an expert in this field who could provide to us any kind of help or guidance.

Today, I would like to tell you from the bottom of my heart, about my psychological process, my grave communication and interpersonal problems with the world around me and my lonely struggle and that of my husband in procuring my rehabilitation.

Before my accident, I had studied modern languages and worked as Executive Bilingual Secretary in Bogotá. I was joyful, dynamic and, after five years of marriage, a happy wife - who anxiously awaited the arrival of her first child. But, an overdose of spinal-anesthesia, applied by a physician at the moment of the child-birth turned me into a deaf-blind and paraplegic person. I remained in pre-agonic condition

for 2 months and, then, I started to gradually awaken with a very confused mind, in the midst of hallucinations. Shortly thereafter I realized that I could no longer see, hear or move my legs. This fact would mark the total collapse of my young life, my dreams and my home.

In our desperate urge to communicate, my husband and I devised a method which would become my means of communication with the rest of the world. Juan José, my husband, placed a pencil in my hand and, holding it with his, he wrote on a notebook and, surprisingly enough, I felt and understood every letter that he wrote. The first thing my husband wrote was: "For the time being, you cannot see, hear, or walk." Then he wrote: "The baby is a girl and my mother is looking efter her." Afterwards, we came to understand that, since I could not see, the pencil and paper were not necessary. We decided to use my index finger as a pencil, and write on any surface. Since then, this method has worked out perfectly for my needs.

The psychological process began with the stages of desperation, wrath, self-abandonment. Then came acceptance of reality, incredulity and the beginning of a fierce inner struggle as my contact with humanity was now blocked out. This brought along the great sorrow of not being able to seek affections, and the loss of my independence and freedom. I stopped belonging to and being a productive member of society.

Besides, I had to face my inability to walk and the health problems derived from paraplegia. Then, I started to reestablish my relationships with relatives and friends and, with their help and that of my husband, I somehow managed to keep my mental, emotional and physical balance.

I learned to read and write Spanish braille; then English braille, thanks to which I have taken several correspondence courses from the Hadley school in the United States - among them: World history, Independent Living without Sight and Hearing, and American History and Literature. In 1981, unexpectedly, the Hadley School honored me with the "Challenge of Living" International Award which I received through the American Embassy in Colombia.

In 1983, with my friends' financial cooperation, I travelled to the United States to attend The Arkansas Enterprises For The Blind Center. It was a long 14-hour trip that required boarding three different planes. At that Center, I received a 6-month training in Independent Living and Communication skills.

In 1985, I participated in the II World Abylimpic celebrated in Bogotá in English-Spanish translation and typing skills. In this event, I was invited to speak before the Second National Convention. In my lecture, and for the first time, I manifested the need to create an Institution for the deaf-blind in Colombia.

In 1986, I prepared a Grade II Braille Textbook for the National Institute of the Blind to be taught at distance to the deaf-blind. Since 1982 I have been working for the National Institute of the Deaf as advisor on Deaf-blindness and English-Spanish translator for the team of professionals working in the Deaf-Blind Rehabilitation Program, based on my personal experience and material I obtain from other countries. In this way, I have been able to initiate the movement toward the rehabilitation of the deaf-blind in Colombia.

Since 1985, the National Institute of the Deaf, jointly with the Genetics Department of the Javeriana University in Bogotá, detected cases of severe visual impairment among the deaf school population. The high incidence of the disease justified a closer investigation nationwide, one which continues until today.

Under the Institute of the Deaf's sponsorship, the Hearing/Vision Impaired Program was created, composed of various professionals and, in which I participate in the area of deaf-blindness. We have focused our efforts towards the structuring of this Program.

In its current stage, the program has prepared diagnose and follow-up cards for each student and conducted workshops with family participation. Besides, it is offering the Mobility, Braille, Sensorial-perceptual Stimulation, Abaccus and Visual Efficiency Development courses. We are also carrying out Inter-Institutionals Seminars in order to give training to the professionals working in the rehabilitation of the deaf-blind. With the students, we use 3 communication methods: Printing on the palm of the hand, Tactile sign language and finger spelling.

The Program for Hearing/Vision Impaired persons covers three main objectives:

1. Early detection of the USHER Syndrome.

2. Rehabilitation

3. Employment Training.

We have had major difficulties in accomplishing this latter objective. We are doing studies on Community Enterprises, Small Businesses and other forms of labor involving family participation.

In order to carry out the work that we have undertaken, we would like to acquire books on Deaf-Blind Rehabilitation and Education. We also need counseling as well as scholarships for the training of Colombian specialists on the Deaf and on the Blind. We would appreciate any help in the above mentioned areas that we may receive from International organizations.

As you may have realized, I have managed to solve the vast majority of my family, social, work-related, intellectual, and perhaps most inportantly, my communication problems. Once I defeated the isolation barrier in which I found myself and reestablished the contact with my relatives and friends, I try to lead a life as pleasant and satisfactory as possible. As part of this effort, I travelled to Chile, by invitation of that country's Television network, in order to participate in their VI Telethon, or Fund Raising for the Handicapped.

As of now, I can say that with courage and love, I have succeeded in driving away the monster in the nightmare I once had. I have learned to be happy in the company of my husband and daughter, the rest of the world and, principally, with my own self.

The Helen Keller Institute for the deaf & deaf-blind, Bombay

Beroz N. Vacha, India

It is in the fitness of things that at the outset I acknowledge through Mr. Stig Ohlson, Chairman of the Standing Committee on Activities of Deaf-blind People of World Blind Union for inviting our Institute to participate at this IV Helen Keller Conference.

In India there is a widespread ignorance about the Deaf Multihandicapped child who is labelled more as a mentally retarded child. That gave us the challenge to prove that it was a Deaf child with other severe problems and not necessarily mentally retarded. It was our desire to create an awareness in our Society and our Country of :
Who is a Deaf-blind Child ?
Where is its place in the Society ?
What is the obligation of the Society and the Government ?
and whose responsibility is it to recognise and implement the Fundamental Rights of this severely handicapped group ?

That gave birth to our Institute - The Helen Keller Institute for the Deaf & Deaf-blind. We named our Institute The Helen Keller Institute for the Deaf & Deaf-blind to perpetuate the memory of late Helen Keller who blazed the torch for the cause of the Deaf-blind .

Our beginning was very modest; with 2 teachers and myself and 3 children (2 Deaf-blind and 1 Deaf Aphasic child) and two small classrooms in one of our teacher's homes with just 15 American Dollars (difficult to believe isn't it?).

Today we have 20 Deaf-blind children and 58 Deaf children and several Deaf-blind children on the waiting list. The reality has been made possible because of our faith in ourselves and in the educability of our children. We firmly believe that "No one is incapable of being taught, and no one can do without education. It is the Fundamental Birthright of a child to be loved and educated".

It is this belief that has sustained us and strengthens us to meet our ever growing challenges in this field - for we are the Pioneering and so far till today the only Institute in our Country.

The theme of this Conference, Communication at all Levels is, I feel, a very appropriate one because Survival and Growth are so inter-related with Communication.

To us Communication means to tap and regenerate that spark of Aliveness in every being which allows him to understand and be understood, to move and explore confidently against odds and above all find a place for himself in the Society.

At our School we follow the philosophy of Total Communication for the entire curriculum. Our goals are:"A Functional Education Where Concentration is more on developing the plus points of our children". After several years of teaching we now have 3 levels of children :
1. The High Functioning Deaf-blind Group
2. The Low Functioning Deaf-blind Group
3. Mixed Group

For the High Functioning group the Curriculum includes :
1. Developing his Body image in relation to other people. This concept is then related to how his body supports him in all his daily tasks, mobility, hurt and pain through loss of balance, sickness etc.
2. Concept of :
Self Help skills for himself as well as supporting and helping a younger child.
3. Mobility :
In every area of his movement and in all the tasks he/she undertakes. Here again we make maximum use of Residual Vision if any (especially for Retinitis Pigmentosa children) and Residual Hearing.
4. Eurhythmics for Body Movement :
Moving to Rhythmic music alone and with other people thereby synchronising these rhythmic movements with his partner.
5. Swimming
6. Yoga
7. All the above 6 areas form the basis for developing language skills through tactile communication (signs and fingerspelling) gradually transferring the child to Braille reading and writing skills, maths skills, environmental studies.

We do try and develop auditory Tadoma skills wherever possible since every child is on a binaural hearing aid.

It is surprising to note that majority of the HIGH FUNCTIONING GROUP IS TOTALLY BLIND AND PROFOUNDLY DEAF.

Our teaching programme is based on 1:1 adult pupil ratio using the Conversation and the Maternal Reflective Method. This High Functioning group is encouraged to interact with Deaf children. This is possible because of our use of Total Communication Philosophy.

All our cultural activities, campings, field trips are so organised that the Deaf-blind child has a support from our Deaf children and at times some normal children. This is our first step and an ongoing process of integrating our Deaf-blind children. As part of our communication goals we have sessions for child to child communication with teacher's support for correct language structures so that after a time the child has to learn to express in full sentence patterns and not just key words as is the beginning of expressive language.

The Low Functioning group goals are :
1. Awareness of their peer group and environment.
2. Developing Self-help skills
3. Mobility in his environment and just basic signs to fulfill his day-to-day needs.

Apart from free education our other free services are :
1. Health and Medical Care with Massage for the children
2. In-service training course for our teachers
3. a) Parent-teacher Partnership programme. 3 of our parents are extremely active in not only supporting their children, but take over other children during shortage of staff.

b) Home-bound programme: twice a month the teacher is with the parents and the child in their own home encouraging the parents to interact with the child and to use the home materials for developing various skills.

4. A Residential Unit for Deaf-blind children residing outside Bombay
5. Providing pre-vocational skills with a view to earning a subsidised living. Three of our low vision deaf-blind boys are already employed in a sheltered workshop.

Our Future Goals:
1. To start a training course on an All India Basis
2. To Reinstate children from outside Bombay into their own home or near their homes into sheltered workshop or secure services with a view to earning and a sense of self-supportiveness.

I would like to end my talk with a quotation which I live with every moment. It is as follows :
"A Hundred times a day I remind myself that my Inner and Outer Life and work depends on the lives of those that have gone ahead of me and therefore I must exert in the same measure as I have received and receiving and hand my work to posterity".

And with these words on behalf of my Institute I acknowledge the support of the foreign organisations :
1. The Swedish Institute for sponsoring my stay in Sweden. I take back with me a rich experience.
2. Perkins School for the Blind & Deaf-blind where I had my first experience in training in 1974 fully funded by the Institute.
3. Institute Voor Doven - St. Michielsgestel, Holland - fully funded.
4. To SENSE and National Deaf-blind League for materials and programming my stay in U.K. fully funded.
5. To Nedelandica - Caritas for a substantial grant in the installation of our Residential Unit.
6. To Misereor, W. Germany, for the Audio Visual, Video and Speech Training Equipment.
7. To Helen Keller National Centre, Long Island, N.Y.
8. To Christoffel Blinden Mission, W. Germany
and last but not the least our thanks to our own Ministry of Welfare, Government of India, to all our Local Donors for making our School a unique place on the Map of India.

Report from Brazil

"Communicating with the world around me", Maria Francisca da Silva

I am almost never with people I can understand. I don't live with deaf people, I live in a home for blind women, were the method of communication is the oral language. This makes me feel inferior, and a failure. But in spite of this situation I at least receive the necessary protection from this home. Some of my blind friends there are interested in communicating with me. They know the manual alphabet, so they sometimes bring me out of the loneliness I live in.

I feel frustrated and sad because I don't live in a home for the deaf. In the city where I live there are no residential homes for the deaf, so I don't have friends around me every day who can spell nice words into my hands and give me friendship. Unfortunately I cannot communicate with all the deaf people I have met. Many of them only use sign language. Others do not know how to use the manual alphabet in my hand. I don't know why, but the majority make the movements of the letters to closed. They tell me it is easier, but for me it is more difficult.

The isolation I live in makes me think that everyone should learn the manual alphabet. Not only deaf persons, but also their relatives and friends, the students in the schools and society in general. The indifference of society to this makes me sad. It is hard to know that there are some relatives; an uncle, a brother, who do not know the manual alphabet and cannot communicate with their deaf relative. This is my situation. Only some of my family know or are interested in learning the manual alphabet. At home where I live I almost don't participate in the routine of everyday life, because only five of the eighteen people I live with know the alphabet, and some of the eighteen women I live with are very ignorant. It would be impossible to communicate with them with the manual alphabet. Thus, I almost live alone with my books, my handicrafts and my writing. I write very much in Braille, and this makes me break out of my thoughts.

My first years of deafness were painful. I don't like to remember those hard days in the school for the blind. I was a blind student and I had a good oral language. I used to write and read in Braille during the first years. Then I became deaf, and I couldn't keep up with my studies; I

became deaf-blind. The teachers were not specialised in educating the deaf-blind. They did not know and were not interested in learning the manual alphabet. The difficulties grew bigger and bigger. Nobody knew how to communicate with me. I became rebellious and nervous. The school wanted me to leave, but I had no other place to go to. A nice man who worked in the library became interested and adviced me to read books in Braille in order not to become ignorant.

In 1970 I went to Sao Caetano do Sul in Sao Paulo, a special school for the deaf-blind that Mrs Nice Tonhozi de Saraiva Loureiro founded. We already knew each other and we used to write to each other. Unfortunately the school couldn't accept me, since it was not a residential school, it only functioned as a day school. If I wanted to study there, I would have to live with my relatives. This was not possible, since my brother was living too far from the school. I went to Sao Paulo where I lived with my brother for three months, but it was no good. It was impossible to live with him. When I returned to Institute Sao Rafael in Belo Horizonte I had lost my place at the school. Then I was sent to live in a home for blind women.

There I lived in loneliness without any possibilities to study. Everyday life was teaching me. I began to react more positively. Slowly I was beginning to live less like an animal. I created some signals for my own purposes, in order to make it easier to communicate with others. I learned the manual alphabet two years after having become deaf. I like to use the alphabet. It is fast and expressive and I feel better using it. I very much like my Tellatouch. It has become my best friend even though some people refuse to use it. The Tellatouch cannot be used without some care. You must punch the keys hard, otherwise the Braille letters will not be clear. It can be used rapidly, but that is pressing.

I am trying to learn sign language, and whenever it is possible I ask my deaf friends to teach me. I think this is a good way of communicating. Unfortunately I don't have much opportunity of practising it, since I don't live with deaf people.

Loneliness is the greatest problem of the deaf-blind. Loneliness was always my friend. Today I know how to get along with my difficulties,

and I try to overcome all obstacles. On April 7, 1975, a met e person, a volunteer, who came to be very important in my life. She began to visit me once every week. She helps me to read the correspondence, and transcribes into Braille. Every fortnight she gets me books in Braille from the public library. She tries to help me resolve my problems and my difficulties. She is the light in my life and she helps me out of my loneliness a little. After I met her I became more aware of other people in the town I live in. I also became more optimistic and learnt to enjoy life. She understands my limitations.

When I go to Sao Paulo I get in touch with Mrs Nice Saraiva Loureiro and some other friends. I usually stay for two or three months with my brother. I feel happy because they give me nice moments of happi-ness. Mrs Nice Loureiro got in touch with the Association of the Deaf in Belo Horizonte City and told the president about me. He visited me an d introduced me to some deaf people, and some of them became good friends. The president himself is deaf and he has become a close friend. Through him I met the president of the National Federation of Education and Integration of the Deaf (the office is in Rio de Janeiro), and then I met even more deaf people. Through these friends I have got more in touch with deaf people, and I have also had the opportunity of attending symposiums and conferences where I have told people about my life. Mrs Loureiro has interpreted for me.

It would be wonderful if we could have as many volunteers as other countries, but volunteers and friends must learn to understand and respect the feelings of the deaf-blind. I could tell some both funny and sad stories about this. I become sad and frustrated when someone in my family or a friend do not do something I ask for, such as help me visit somebody or go some place. One day my niece told me "If the person would like to see you, he would come to you." So my wish would only come second. I think this is wrong, The wish is mine, the heart is mine. It is not right to decide for me, and to bring me where they want instead of to where I want.

I like to have friends, but sincere friends. Friendship is a deep feeling. It is to be brothers, to exchange ideas, to suffer or be happy together. A friend is someone to trust and to ask for help when you need it. I have some good friends. I have good friends who can hear, see and talk. I have good friends who are blind. I have good friends who are deaf.

Friends, I trust you. I need your help to get our of my isolation a little. I need human beings. I need your touch in order not to feel my loneliness. Your friendship is very important to me.

Report from Brazil

"August 1987–August 1989", Nice Tonhozi de Saraiva Loureiro

In my work for the deaf-blind of Brazil I have managed some activities in spite of tremendous difficulties. I have finally managed to establish a Section for help for the adult deaf and deaf-blind. This Section is located in on of the regional offices of the Federation of Social Activities, whose regional officer, Miss Olimpia Ana Santana, has made great efforts to develop our programme. We have given orientation to Roberto Ezias, 28 years old and deaf-blind, who studied at the Special School for the Deaf-Blind in Sao Paulo, and Alessandra Carneiro, a young girl of seventeen who is deaf and a slow learner, and who has never been to school.

With a lot of hope and persistence we put all our efforts into developing the programme. The main purpose is to offer conditions so that the deaf and the deaf-blind have the opportunity of maintaining and developing what they have learnt during their formal and informal education. We also want to offer them possibilities to experience life within the community. This emphasizes the need for maintenance of and development of communication methods, and rehabilitation for work and leisure. To stimulate this we use reading, educational games and excursions.

The two students mentioned above also learnt some handicrafts. They have already learnt how to make handbags, mats for cans, and paper roses. Robert Ezias sells his handicraft, which is very helpful and makes him happy.

Activities:
Maintaining contacts with members of the IAEDB. They send me the newsletter "Deaf-Blind Education" and the English paper "Talking Sense". Keeping in touch with Perkins School for the Blind. They send "The Lantern" and "The Educator". I send copies of these papers to some organizations, special schools and specialists; for instance to the Association of the Deaf and the Deaf-Blind in Sao Paulo, the Brazilian Foundation for the Blind, Special Education College etc.

Attending symposiums and conferences where I present papers about deaf-blindness and interpret for Ms Maria Francisca da Silva, who is herself deaf-blind, who has also given several speeches.

I have also received several awards and honours for my work with the deaf-blind.

General activities:
Participation at meetings of the State Board for Handicapped People.
Visits to two places that work with deaf-blind children; Annie Sullivan Special School for the Deaf-Blind and the Deaf, and the Association of the Deaf and the Deaf-Blind.
Participation in research and preparation of a group of actors that are putting on the play "Between Hands", a play about the adult Helen Keller.
Correspondence with deaf-blind people in other parts of Brazil.
Translations of material on deaf-blindness for specialists and special schools.
Trying to get in touch with the authority responsible for the twin babies who were born deaf-blind in the very poor little town Pará in northern Brazil. The babies were born in a very poor family and were later adopted by a Belgian couple.

Conclusion:
The difficulties are the same as always, maybe even worse. Our country is suffering a tremendous economical, political and social crises in all sectors of the society, and the situation is especially bad in special education. The incomprehension of the authorities and their indifference to this special field shows us that there is still a lot of work ahead of us to develop services for the deaf-blind. A deaf-blind Brazilian child is at the Perkins School for the Blind in the USA, where the parents find a good structure and hope and confidence that their child will receive a good education. The twin babies that were adopted by the Belgian couple will also receive a better education. It is sad to realize that many other children will be kept at home because they live too far away from Sao Paulo, where there are two schools for the deaf-blind. The adult deaf-blind live as they can, getting help from their family and friends in order to get out of the silence and darkness they live in.

Fortunately, there are in the new Constitution things that benefit disabled people, in legal and other aspects. A future census will be made so that we will know the number of disabled people in Brazil. This will make it easier to find the deaf-blind and to help them.

We must always ask for help from private organizations, and from friends that understand and trust us. I want to thank them all.

Report from Canada

Karen Fleming

There is an estimated 2000 deaf-blind people across Canada. However, there are no accurate statistics available. Each province defines deaf-blindness differently and there is no consistency of services throughout the country. There is a need for one uniform definition and accurate statistics to be gathered across Canada.

Ontario has the most comprehensive services available to deaf-blind persons. There are a known 300 deaf-blind persons in Ontario and an estimated 300 who have not been identified. In Ontario a person is considered deaf-blind if the combination of hearing and visual loss is severe enough to interfere with an individuals daily life.

So far, there are two major organizations that are responsible for providing services to deaf-blind persons in Canada. They are The Canadian National Institute for the Blind and The Canadian Deaf-Blind and Rubella Association. The CNIB serves any deaf-blind persons requesting services. CDBRA is primarily a parent advocacy group for the congenitally deaf-blind and speaks for those deaf-blind that cannot speak for themselves.

CNIB Ontario has a separate office for Deaf-Blind services with 19 full-time staff and 17 part-time staff. About fifty percent of the funds are provided through the provincial government and the other fifty percent comes from CNIB and private donations. A variety of services are available at no charge to the deaf-blind individual. These services include counselling, orientation and mobility, referrals, assistive devices, activities, recreation and intervention. An intervenor is a person who bridges the gap between the deaf-blind person and the hearing sighted world. An intervenor becomes the eyes and ears of the deaf-blind individual and assists the person with such tasks as shopping, banking, attending doctor appointments etc. The intervenor may also act as a teacher when required to teach cooking, budgeting etc. Currently deaf-blind individuals receive approximately five hours a week or less for intervention services. There is a need for more intervention but funding remains a problem.

In New Brunswick, the CDBRA serves deaf-blind people. CDBRA applies for funds for intervenors for each deaf-blind person. Generally, services in Eastern Canada are very limited. Western Canada now have Case Managers for Deaf-Blind Services in a couple of provinces but services are still very scarce. Quebec has no consistent services, and little contact with the rest of Canada. Service are provided to culturally deaf individuals who have a visual impairement through the Institut Raymond Dewar for the deaf.

There is a wide variety of communication modes used by deaf-blind people in Canada. About 50% of deaf-blind people use sign language or know it. About 60% of the deaf-blind population has Usher's syndrome, and have grown up deaf. About 20% of the population is congenitally deaf-blind. This figure was elevated between 1963-1965 due to the Rubella epidemic. A large number of congenitally deaf-blind children are educated in the deaf-blind unit of a school for the blind or a school for the deaf. This group will generally use sign language, although often at a very basic level. Others who grew up hearing blind or hearing sighted will be oral and rely on the two hand manual for receptive purposes. A number of individuals use large print notes as their primary mode of receiving communication. There is only one person in Ontario who uses the Tellatouch as his primary mode of communication. Due to the wide variety of communication modes used by deaf-blind persons, it is often difficult for deaf-blind to communicate together. In Canada we are attempting to bridge this gap by having the two hand manual as a common communication form that everyone learns as it is easiest to learn. Two hand manual is a secondary language for everyone and it at least provides a common ground so we can communicate with each other.

There are a lot of aids and devices available for deaf-blind people. The most popular device is a vibrator alert such as the Silent page in which a band worn on the wrist and vibrates to warn the individual of sounds such as a telephone ring, or door bell etc. A vibrating wake up device is also popular. The second most popular is the Close Circuit T.V. A lot of people use a T.D.D. We have recently got a large print T.D.D. which seems popular to date. There are only 3 people in Canada who make use of a Telebraille (Braille T.D.D.). A lot of people across Canada do

not know about the various aids and devices that are available. Another factor is the expense of such equipment. CNIB in Ontario does have various devices that can be loaned out to people. Ontario has a program under the provincial government known as assistive Devices Program which pays for 75% of devices developed specifically for deaf-blind people. The other 25% is paid for by the individual if he/she can afford it or by CNIB or a service club. Unfortunately, large print T.D.D.s and C.C.T.V.s are not included in this program. Vocational Rehabilitation Services, under the government will only pay for equipment for individuals who need it for their job. V.R.S. will only support individuals who are training and have the potential of gaining competitive employment. Unfortunately there are only a few deaf-blind people who fit in this category. Therefore a number of people cannot obtain high tech equipment, only basic signalers etc. Most people are concerned about devices that will enable them to live independently.

There are only a few deaf-blind people who are of working age that are competitively employed. Again it is difficult to give accurate statistics as we do not have them. Now under 50% of the deaf-blind population is competitively employed. There are a number of others who are in semi-sheltered workshops. Most are on Family Benefits Allowance (F.B.A.) which is a disability pension from the government. Part of the problem is a lack of understanding and awareness of deaf-blindness and a lack of intervenors for on the job support.

Independent living is an area of concern for deaf-blind individuals. We have no statistics available for Canada, only Ontario. Deaf-blind people are living in a variety of places now. Some live independently in an apartment in the community and use an intervenor to help them with shopping etc. Some live with family, either parents, spouses or sisters and brothers etc. Many are married with children of their own. There are 4 group homes in Ontario that have been set up for congenitally deaf-blind people who require more support and supervision. Saskatchewan has 1 such group home and British Columbia has 1. These have been set up by CDBRA.

Currently Ontario is able to serve 18 in their group homes, Saskatchewan serves three and B.C. serves one. Many other deaf-blind people are in institutions, nursing homes and residences or group homes for the deaf or the blind.

Currently, Ontario has begun to work on a housing project for deaf-blind individuals. Funding has been given by the Ministry of Community and Social Services, the Minisitry of Housing, the Rotary Cheshire Club and the Canadian Foundation of Disabled Persons. The Rotary Cheshire Housing Project (RCH) is currently looking for a site on which to build the apartments. This project will consist of 16 independent fully equipped apartments for people who are capable of living independently. There will be approximately 4 hours per day of intervention provided for people living in the apartments. There will also be an Intervenor on call 24 hours a day in case of emergency. It is very difficult to find a site that is affordable as well as accessible and on a direct bus route.

The Canadian National Society of the Deaf-Blind (CNSDB) is run by deaf-blind people across Canada. We are a consumer advocacy group and we try to help ourselves. We represent the deaf-blind population at a national level with the government, assist in projects etc. designed to help deaf-blind people. We are also involved in public awareness programs and have organized a convention for the deaf-blind. There is a magazine for the deaf-blind called "Dots and Taps". This is published quarterly in large print and Braille. The CNSDB also prints a Newsletter. The CNSDB consists of both full members who are deaf-blind individuals and associate members who are intervenors. The national executive of the CNSDB consists of 4 deaf-blind members and 4 associate members. Full members get two votes whereas associate members have one vote. Currently we have 34 full members and 43 associate members who have paid membership for 1989-1990. The executive has monthly meetings. However, much of the correspondence and meetings take place by mail due to the distance.

There are five local clubs that are associated with the CNSDB. They are located in Toronto and Ottawa, Ontario, Edmonton, Alberta, St. Johns Newfoundland and Vancouver, British Columbia. These local clubs usually meet monthly and provide activities and a chance to meet and socialize for the deaf-blind members. CNSDB itself is still fairly new and has only existed for the past four years. The idea for CNSDB originated from the Deaf-Blind Association of Toronto which is 28 years old.

Thank you all for allowing me this opportunity to report on Canada and the deaf-blind population.

Report from the Federal Republic of Germany

"The German Educational Centre for the Deaf-Blind, Hanover; functions and objectives", Ferdinand Zekel

The German Educational Centre for the Deaf-Blind in Hanover was founded in 1967 as a non-profitmaking organization. In the Federal Republic of Germany school education for deaf-blind children was begun in the year 1964 at the Hanover School for the Blind. During the period from 1969 to 1972 a separate educational and residential institution for deaf-blind children, teenagers and adults was established. This has become the Educational Centre for the Deaf-Blind with a residence for deaf-blind adults in Hanover-Kirchrode.

The German Educational Centre for the Deaf-Blind represents the socipolitical, economic, educational and social interests of all deaf-blind people in the Federal Republic of Germany. There are currently 92 deaf-blind school pupils at the Educational Centre for the Deaf-Blind and 50 deaf-blind adults in the residence facility.

The number of deaf-blind people in Federal Republic of Germany is estimated at 1500. In this context the definition of deaf-blindness is very narrowly restricted. In the "Recommendations for Instruction at the School for the Deaf-Blind", published in 1985, the definition is as follows:

"Deaf-blindness is a handicap of a characteristic nature which cannot be defined by simply adding up deafness and blindness. Deaf-blindness refers to a handicap resulting from the impairment of vision as well as hearing. Since both of the senses which enable a person to percieve things from a distance are affected, the loss of the one sense can, at best, be only insufficiently compensated for by the other. Thus psychosomatic development is frequently affected even in cases of relatively minor individual impairments. Deaf-blindness may be found in conjunction with any other impairment or handicap."

The German Association for the Blind consists of 15 organizations for the individual Laender. It has numerous groups specifically for the deaf-blind. These groups are run by deaf-blind or blind people and

organize their own events including counselling and one-week training courses. The German Association for the Blind provides the periodical "The Deaf-Blind", The Association's own publication "Self-help for the Blind" and the periodical "Woman's World" as well as magazines from the Roman Catholic Agency for the Blind and the Christian Service for the Blind free of charge to all deaf-blind Braille readers. For more than thirty years the German Association for the Blind has organized three-week recreational holidays for deaf-blind people. These activities are planned and supervised by the responsible deaf-blind spokesman in the Association. The Roman Catholic Agency for the Blind and the Christian Service for the Blind also invite our deaf-blind friends and their helpers to take part in recreational events. The German Educational Centre for the Deaf-Blind conducts further education seminars for people who work with the deaf-blind in a professional or voluntary capacity. These seminars always aim at combining theory and practice. Since early 1989, German Association for the Blind has been supplying "News for the Deaf-Blind" in Braille free of charge five times a week.

As far as the available building space and personnel is concerned, our school for the deaf-blind in Hanover-Kirchrode is in a position to serve the educational needs of the deaf-blind in the entire Federal Republic of Germany. A total of 29 deaf-blind and special subject teachers and over 100 residence counsellors currently care for and instruct 92 deaf-blind children and teenagers. Seventy percent of these young people are multiply handicapped as a result of rubella infection. The residence facility for deaf-blind adults is also large enough and is well staffed (50 deaf-blind adults up to 91 years of age are in the care of 30 staff members).

In the future, the main emphasis of our work will be the expansion of early care and early education services for deaf-blind children of pre-school age, including parent counselling services, and the establishment of a separate department for the rehabilitation of deaf-blind adults. (The target group will be deaf or hearing impaired individuals whose vision is failing and blind or visually impaired individuals whose hearing has worsened or been lost for reasons of health and of age.)

Although the number of individuals with sensory impairments is decreasing, multiple handicaps are on the increase. Contrary to our expectations, the experience of the past 16 years has shown that, after completion of their schooling or after vocational re-training in our institution, the majority of the deaf-blind can neither return to the parental home nor find accomodation in another facility close to the parent's place of residence. These individuals are very seriously handicapped in their personal development. Throughout the Federal Republic of Germany experience has indisputably demonstrated that, even as adults, they require the surroundings of a residence facility, workshops and therapeutic measures. Accomodation in existing institutions for the "mentally handicapped" is not an adivsable solution, because it is obvious that the multiply handicapped deaf-blind would never feel at home there. Because of the primary handicap resulting from a visual impairment in conjunction with a hearing impairment, they would become isolated among the large number of other residents. Therefore, the German Educational Centre for the Deaf-Blind has endeavoured to construct its own facility for multiply handicapped deaf-blind individuals.

In accordance with the explicit request of the Ministry of Welfare and Social Services of Lower Saxony multiply handicapped blind individuals will also be accomodated in our new institution for the multiply handicapped deaf-blind.

At the present time a residence facility and a workshop for 71 handicapped individuals is being constructed in Fischbeck approximately 60 kilometers southwest of Hanover at a cost of about 18 million German marks. The plan forsees a complex consisting of several on and a half story buildings which are structurally connected for reasons of personnel organization (helping out in cases of illness, night duty etc).

In each "house" there are 7 single rooms, a large living and dining room, a kitchen, bathrooms and a separate terrace. A large central kitchen supplies the occupants and staff of the individual "houses" with a cooked meal at midday. Breakfast, supper and any occasional snacks are prepared in the separate kitchen of each "house" and eaten at the family table. The handicapped occupants are given assistance with household chores and with tasks in the workshop, where

for example simple industry contracts are executed. The property has a total area of almost 56.000 square meters. It includes an adequate number of walking paths and a small greenhouse for gardening activities, which are to be introduced on an experimental basis. Unfortunately, the plan for an indoor swimming pool had to be abandoned for financial reasons.

The financing of the entire project was accomplished in the form of subsidies and low-interest loans from the land of Lower Saxony, the Federal Republic of Germany, the Federal Labour Agency, the German Educational Centre for the Deaf-Blind and its shareholders (the German Association for the Blind, the Lower Saxony Association for the Blind and the German Non-denominational Charitable Agency), further the city of Hessisch Olendorf to which Fischbeck belongs and many others. The new institution will open in the spring of 1990. The first guests it will accomodate will be 17 multiply handicapped deaf-blind individuals from Hanover-Kirchrode.

Report from France

"Communication", Nicole Levy

Dealing with communication problems of the deaf-blind implies considering those faced by persons who were blind to begin with, and still have residual hearing and who are able to gain by some appropriate hearing aid. There is not one specific case as regards deaf-blindness and I can only speak for myself, from my personal experience.

1 Several problems are interwoven in the perception of deafness, a specific deafness (measured in decibels), thus we have to distinguish "the response time to noise" - more or less delayed according to the degree of deafness - from the difficulties encountered in social relations (ability for conversation, for instance). Noise is aggressive, but I am not always able to hear it as quickly as a hearing person, or to understand and locate it, for instance heavy traffic, road maintenance or similar work, the wind amplified by my hearing aids. As a result, it is sometimes difficult to cross the street safely on my own, and I can't get information from passers-by. These aggressive noises lead to a permanent state of nervous stress.

2 Social relations or problems linked to conversation: I have no problem voicing my message (my deafness happened quite late and had no effect on oral language acquisition). On the other hand, expect for phone calls which are almost satisfactory thanks to the addition of an induction coil inside the receiver, there are a lot of problems:

> The accoustics of a room are very important; height under a ceiling and floor and wall covering affect a resonance phenomenon leading to phoneme distortion, so I need to be accompanied by somebody I understand well in public service premises, hospitals etc.
>
> In the same way, I am deprived of any communication in a room where many people are gathered, or which has bad sound proofing or where there is noisy music, because the noise volume drowns the voices of the people willing to talk to me.

3 Problems linked to conversation (understanding curve):

> One gets used to one voice and it is very difficult to follow several voices, which means that I am banned from any group discussion. I can talk with one or even two persons in a quiet room if they stand either beside me, or just in front of me and not further away than 70 cm, so that the sound gets to me directly.
>
> An excessive volubility, as well as a slow and too articulated pronounciation, affects my ability to understand. Difficulties arising from foreign or regional accents, from announcements by intercom or loudspeakers (in stations, trains, planes etc.) have also to be noticed.

In order that cerebral decoding may be done under the best possible conditions, a clear voice, and a delivery close to standard, are required for sounds recognition.

Can miracle solutions be suggested? Of course not!

Research in auditive prostheses is in a process of evolution; but for the moment it is only profitable for either the kind of persons who could not have hearing aids before and who, even if they don't have access to a verbal message, can now benefit from a significant sonorous environment, or for persons with average or severe deafness who are offered an excellent auditive correction by internal hearing aids. These small prosthesis are completely set inside the ear. Such a miniaturization is of no use to profoundly deaf persons for whom only external hearing aids are possible. There is a significant difference between internal and external hearing aids; the location of the microphone which is usually at the back of the external ones, posing problems about locating noises - origin and direction, and the internal ones have no parts that need to be changed frequently.

It is noticeable that, while audio prostheses have become constantly better for the last quarter of the century, there has been almost no improvement in hearing aid parts; the material is a bad conductor and causes allergies which have serious consequences in the long run.

Lacking auto-regulating prosthesis, it would be desirable to have pocket devices, remote control devices, like those of television sets, which would be of common use, with an easy, accurate and quick system of adjustment according to the sonorous environment or the various pitches and noises.

Few technical aids like synthetic voice readers are accessible to most of us, and those issuing the text in Braille are too expensive, not reliable, and difficult to manipulate.

During work meetings and official visits, I use a portable tape-recorder, with a headphone and a microphone, which enables me to follow the discussions satisfactorily, and also to take part.

Obviously, so many constraints have psychological consequences, I went through nervous breakdown periods, with aggressive reactions. Even now, when more or less well-meaning persons are screaming in my ears - because of my deafness they say - I sometimes feel it is impossible to keep my cool. However, I try to explain to the people I am speaking to how inefficient and painful for me, and tiring for them, this way of doing it is. We had better talk in a quiet place, standing at a reasonable distance from each other, and if necessary, speaking just a one tone above the average. When admitted, these explanations always contribute towards easing and settling excellent social relations.

I know perfectly well that, on the one hand, I still have a lot of efforts to do, for instance to learn other means of communication; I use TELLA-TOUCH a little, I also write in the hand, but I have not had the will-power to learn finger spelling or sign language yet. At last, and above all, I'll have to accept my deafness as it actually is: a profound deafness, and a real barrier between me and society! This difficult acceptation is necessary, but it is not obvious.

Report from Italy

"Kalorama", Rita Lubrano

I would like, in my presentation to describe briefly the community "Kalorama" of the Lega del Filo D'Oro and above all define some of those services which should be developed to assist these people.

In this community "Kalorama" there are actually 12 deaf-blind adults living in three apartments in the city of Osimo which is close to Ancona. The people living in the community have the use of workshop type activities of a handicraft nature. (Weaving, basket making etc.)

The services have as a primary objective the development of personal independence and occupational work abilities, according to the individual characteristics of the deaf-blind person, and to facilitate the integration into the local society.

When I talk about deaf-blind I am referring to those who have only a sensory handicap, those persons who have normal intelligence and live normal lives when it comes to emotions and relations.

It seems to me that the following services should be assured in favour of the deaf blind-adult.

1. One intervenor for each deaf blind person, at least in the beginning, to enable maximal development of ones own personality and intelligence. The role of the intervenor is extremely important in so far as they can assist the deaf-blind to overcome the psychological problems which the person may have, and also to discover the real motivations of the deaf blind person and orient them towards an activity which is satisfying and rewarding, as well as to encourage the intellectual development by means of studying. I for example was deprived of the possibility to continue my studies, when my disablements prevented me.

2. Work activities which could be available to the deaf-blind are in printing, engraving in relief, bookbinding, manufacturing of various products other than basket weaving, mending chairs and knitting. The

activities for the deaf-blind should, when useful and dignified, make social integration possible. A factor which to me seems important, is that in rehabilitation one should distinguish between those who are blind from birth and those who are deaf from birth, in so much as they have such a different representation of the world and perception of things.

Lastly the communication. Every system of communication used is valid when functional; maybe it would be opportune if there existed just one system, used by all nations. The discussion concerning communication should be seen in a more general perspective within the education of deaf-blind people, since it it by means of communication one can welcome all those people who would like to give their friendship.

This vision is far from the actual state of things, but I hope that all together and with all of our force we can achieve this goal.

Report from the Netherlands

Paul van den Berg

The Dutch Union of the Blind and Partially Sighted have a special committee consisting of people who are visually and auditory handicapped. It was established six years ago by the interested themselves. Since then, it has worked on its consolidation. About 120 people with the double handicap have become members of the group.

In the early part of this year it was officially accepted as a Contact Group within the Union, which gives them freedom to act on their own initiative not only inside the Union, but also in their contacts with external groups working in the same field. They are now preparing information material about the problems and activities of the deaf-blind, especially intended for the general public, and a folder, intended for medical practitioners and specialists, in which attention will be paid to some important points in this sphere.

Once or twice a year the group organizes national days for its members during which a special subject is treated. A weekend offered by the Union (Dutch abbreviation: N.V.B.S.) on independency training appeared to be a success.

There are good contacts with the recently established union Oog-en-Oorzak, which is not only intended for the deaf-blind, but also for the families of the same, relatives and interested friends. It is the intention that the greater part of the board will be formed by the visually and auditory handicapped themselves.

The early initiative to form this group was born during a study meeting organized by the Stichting Doof-Blinden (foundation for deaf-blind adults, leader Mrs Anneke Balder). A number of participating parents felt a strong need for more contacts with other people in the same situation, in order to help one another by discussing their special problems.

The Stichting Doof-Blinden also organized courses for volunteers and interpreters to assist deaf-blind persons as guides. Recently this

foundation organized an information day for medical practitioners on the subject of deaf-blindness.

We hope that in the next few years we can make more progress in getting the deaf-blind more interested in their own organization.

Report from the Netherlands

"Oog en Oor-Zaak, Nederlandse Vereniging van Visueel-Auditief Gehandicapten en hun Relaties", Jan Foks

Let me first introduce myself to you. My name is Jan Foks, 37 years of age. I have a wife, Rosemarie, and two wonderful children, Jelle and Maaike. When I was 17, I had to have dialysis treatment. My kidneys dit not work. When I was 21, I became deaf-blind in a couple of months as a result of that treatment. Now I have had, for the third time, a kidney transplant. My sister donated one of her two kidneys.

Eye and Ear-Mark.
In November last year, I was elected to the board of Oog en Oor-Zaak, the Dutch Association of the Deaf-blind and their relatives. The name of our association is really a play upon words. In English it could be: "Eye and Ear-Mark". The translation however is: It is a matter of eyes and ears.

We were founded in april 1988. We are an independent association. The board has 11 members. Six of them are deaf-blind. This month we have 70 deaf-blind members, 30 relative-members and 56 supporting. Money is always, as for many other organizations, our main problem. All the members have to contribute and we also get donations from organizations and individuals. It is thanks to the Institute for the Deaf, in St Michielsgestel, that we were able to join The Fourth Helen Keller World Conference on Services to Deaf-Blind Persons. Our most important aim is taking care of companions. But we are also bring up things of collective interest and give information.

Sections and committees.
Our association has three sections,

1. Section "Deaf-visual handicapped"

2. Section "Hard of hearing-visual handicapped"

3. Section Relatives,

and several committees. A section works for just a part of the members, a committee is busy with things of common interest. For example:

a. The Drafting-committee. Every month we put out the "Eye and Ear-Journal", with interviews, stories people write by themselves, news about aids and appliances, etc.

b. Committee on Independent living. There are not enough possibilities for independent living for the adult deaf-blind.

c. Committee on Interpreting. One of our aims is : More interpreting-hours for social contact. A deaf-blind (or deaf) person can only claim 18 hours a year. For example: The board meets every month. Just for those meetings I need more hours. And then I don't talk about the two committees I just mentioned and which I'm on.

Activities
We organize meetings for all sections separately and for all members together. For example: The deaf-visual handicapped section went tandem-cycling at the island of Texel (all organized by themselves); the section relatives is going to visit Kalorama, centre for the deaf-blind in Holland.

One organization
We hope to have one organization for things of collective interest soon. Now we have two of them in Holland. There also is the "Contact-group Visual-Auditive Handicapped". They are members of the "Dutch Blind and Bad-Sighted Association". We have already arranged a meeting so that we will be able to co-operate.

Report from Norway

A report on the lives and health of the deaf-blind of Norway, based on interviews made by The Association of the Norwegian Deaf-Blind in cooperation with Statens Sentralteam for Dövblinde.
Karl Jacobsen, Finn Johansen, Reinholdt Robertsen, Björg Simensen

We would like to acknowledge Ann Marie Fröyland and Ruth Robertsen who acted as interpreters and took active part in the discussions at the various meetings that were held in connection with the survey.

Introduction

Deaf-blindness is a functional handicap which makes it difficult to communicate. This led to problems in the social life of most deaf-blind people. You become isolated, have little access to information and find it difficult to take part in cultural and social activities. Deaf-blindness also impairs the mobility. In this knowledge, several things have been done to lessen the difficulties. It has for instance given rise to the work that is being done with contact people. We have tried hard to find a contact person for every deaf-blind that wants one, since it could break the isolation in which many deaf-blinds find themselves.

There is also adjustment and adaptation courses for deaf-blind, to help them function in the best way possible in spite of the obstacles. There is an interpreter/intervenor service, and a news service for the deaf-blind. In our report we have looked at how much these services are used, and, in some cases, what the deaf-blind feel think about them.

Surveys on deaf-blindness have been made before in Scandinavia. All these have been of an empirical nature and have been held on an objective level. A Finnish survey was of a more subjective nature, and some have been completely subjective, as for instance the Swedish "From Morning to Night" which is based on the lives of six deaf-blind persons in Sweden. Surveys such as these are small and based on a few individuals (case stories).

After an objective survey has been made measures that are aimed at the deaf-blind population as a whole often follow. A more subjective survey often leads to measures aimed at an individual. The need for

aids and devices has amongst the deaf-blind has often been looked into. A report on the technical aids that are available was published in Norway in 1985. There are also a few other works on deaf-blindness published by NUD, the Nordic Centre for Educating the Deaf-Blind.

This report is empirical with subjective elements. We look into several areas that have not been examined before, such as health. It differs from earlier reports in that it has been conducted by deaf-blind people. They have picked the areas examined and they have drawn up the questionnaires together with professionals.

In the report we evaluate some of the measures taken to help the deaf-blind. The report throws light on the health status of the deaf-blind. Since the report deals with several areas, it does not penetrate any of them more than superficially. The results show, however, that more penetrating examinations of these areas would be interesting.

Method

The report is based on interviews. Questionnaries are an easy way of collecting information but there are weaknesses in this method. We have tried to avoid them. There are very few "open" questions in the questionnaire; nearly all the questions have several alternative answers. When we feel that the way in which the survey is conducted has influenced the answers this is indicated in the report. It is difficult for the deaf-blind to acquire and understand information. and this is a possible source of error in the report. To avoid this source of error, those who needed it have had an intervenor or a contact person to help them fill in the questionnaire.

The deaf-blind may be split into two groups :
Those that are born deaf-blind and those that become deaf-blind later in life. Our report is based on the latter group, which in turn can be divided into three groups :
1. Those that are deaf or have impaired hearing and become blind or have their vision impaired later in life.
2. Those that are blind or have impaired vision and become deaf or have their hearing impaired later in life.
3. Adults, whose vision and hearing becomes severely impaired.

The number of people who had become deaf-blind as adults was 182 in Norway January 1, 1988. 89 of these received the questionnaire and 58 of them filled in it. Those that answered were divided into two groups, based on the following criteria :

Group A: Those that are members of the Association of the Norwegian Deaf-blind and/or have attended adjustment courses for the deaf-blind at Eikholt centre in Drammen. They answered the questionnaire at the summer convention. All of the 44 deaf-blinds present received the questionnaire and 37 filled it in. The result was presented at the Nordic Conference for the deaf-blind in Vettre 1987.

Group B : They are not members of the Association of the Norwegian Deaf-blind, have not attended any course and do not take advantage of the services offered the deaf-blind. The questionnaire was sent them in mail together with instructions. All 45 persons in this group received the questionnaire but only 13 returned it to us. Two of these had been too ill to fill it in, so there are only 11 answers from this group. It is reasonable to expect that the deaf-blind should have difficulties in filling in a form such as this, but the percentage of answers from this group is so low that it must have other reasons as well.

The results presented in the report are based on all the 48 answers. Some of the questionnaires have not been completely filled in. The percentage of affirmative answers is based on the number of answers, not on the number of questionnaires. In most of the tables the answers from group A and B are presented together. They have only been presented separately where it is of interest to the results. The number of people in group B is so small that it is not meaningful to treat it separately. We do not know whether the 11 answers are representative of the group.

Results and discussion

Of interest in the report is the lack of response from group B.

Table 1	Number of questionnaires	Answers	%
Group A	43	37	86
Group B	44	11	25

The table shows how many questionnaires were sent out and how many of those that were filled in. 9 out of 10 in group A answered, but only 1 out of in group B.

The lack of response from group B is expected, since a questionnaire is difficult to fill for the deaf-blind, but this cannot be the only explanation. It means that the survey tells us more about group A than group B. A possible explanation for the lack of response is that many in group B live in institutions and are incapable of, or do not wish, to be part of surveys like this one, since they, or people around them, feel that it does not really concern them. Another possible explanation is that the people in group B do not wish to keep in touch with the deaf-blind community. This could either be because they did not need to avail themselves of the services offered when they became deaf-blind, and as time has passed it has become difficult for them to get in touch with those that administer those services. It may be that they want to manage on their own. So the explanation for the lack of response may be that group B consists of deaf-blinds in institutions and deaf-blinds who do not wish, or find it hard, to get in touch with the deaf-blind community. To find out who the people in group B are, we have looked at their living arrangements. 1 out of live in institutions, while 3 out of 4 live with their families or at their own. This seems to show that group B consists of deaf-blinds in institutions or deaf-blinds who do not want, or find it hard, to use the services available. It is startling to find that we do not know the people of this group, or their needs. It shows us that we are only familiar with the deaf-blind that avail themselves of the existing services. This argues in favour of decentralising the work for the deaf-blind. You could for instance have deaf-blind consultants in each part of the country. If there were four such consultants they could each stay in touch with about fifty deaf-blind persons. This would give us knowledge about all the deaf-blinds in Norway, whether they belong to group A or B.

Biographical Data

3 of 5 have been/ are married. In the population as a whole 9 out of 10 have been/ are married. The knowledge is important, since it shows that many deaf-blinds live alone. When it comes to where they live; a flat, a house etc, they do not differ much from the rest of the population of Norway, but the fact that 2 out of 5 live alone sets deaf-blinds apart.

This is important to remember when you deal with the problems of all the deaf-blind in Norway.

Contact persons

3 out of 5 have a contact person. Unfortunately only 1 out of 3 has had the same contact person since the start of this project. 3 of 4 do set things together with their contact person, which shows that they use them actively. When asked how important the contact person is, 4 of answered that they are important or very important.

Table 2
How important is the contact person to you ?

Very important	Important	Of some importance	Of little importance	Not important
15	10	2	5	1

The table shows that 25 of 31 deaf-blinds felt that the contact person was important or very important. Those that did not have a contact person show by their answers that they would like to have one. A few of them had asked for, but not been granted, one. The results show that the contact person project is very important. This is shown by the fact that those who had one felt that it was important to them and by the fact that those who did not have one did, in most cases, want one.

Interpreter/guide

Most deaf-blind people depend on an interpreter/guide to be able to get anywhere out of doors, even if they do not need help within a small, well-known radius. Most of them also need an interpreter when in conversation with people who are not familiar with the methods of communication amongst the deaf-blind, or at meetings and lectures.

Our survey shows that 3 of 4 have an appointed guide, often, 2 of 3, a friend or a relative. 1 out of 3 has professional help.

The interpreter/guide service is a fairly recent thing in Norway. It is hard to find qualified interpreters and guides. Another problem is that there is no agency for supplying them. There is no full time employment for the interpreters/guides, so they must have other jobs as well. This means that it is difficult to find someone during normal office hours. The service is beginning to function better, however. It is specially important to those that live alone.

Adjustment courses

The Association of the Norwegian Deaf-Blind, FNDB, arranges adjustment courses for the registered deaf-blind. (Group B in our material have not been to any such course.) In group A , 7 people had never been to an adjustment course, 6 had been once, 9 twice, 3 three times and 8 people had attended a course 3 or more times.

We did not try to find out how important the courses had been to those that had attended. The results show, however, that most people return to the courses several times, while there is a small group that do not attend the courses at all. The goal is, of course, that all deaf-blind people should attend at least one such course. It is difficult to guess why some people never attend these courses. Information and motivation are needed to ensure more people at them. Here again one sees the need for a more decentralised and closer contact with the Norwegian deaf-blind in the form of deaf-blind consultants.

Society as a whole

Deaf-blind people are in touch with society as a whole through associations, newspapers, radio, television etc. Their handicap makes it difficult for them to acquire information, so a new service for the deaf-blind has been started. Our survey has not gone into how much the different media are used, neither have we asked how the users feel about them. We have not tried to find out whether some people use many different media, while some do not use any at all. The deaf-blind seek their information in the news service for the deaf-blind, in newspapers and TV. 3 of 5 are members of an association. 4 out of 6 use the news service, 4 of 6 read papers, 2 out of 6 listen to the radio, 4 of

6 watch TV. As the figures show, many deaf-blinds use their own news service. To find out how this service is used in relation to other media you would have to examine this area in more depth. Our survey shows that the deaf-blind use different sources to gain information.

Social network

By social network we mean the people a deaf-blind person is in touch with. In daily life three groups of people are important.
1. Husband/wife, children. 1 of 3 are in daily contact with these.
2. Relatives friends. 1 of 5 are in touch with them daily.
3. Other deaf-blind. 1 of 4 are in daily contact with these.
In group A, 12 people had no one with whom they are in touch daily, this means 1 of 3, apart from home help or other professionals. We have not looked into how this affects them, but it is an important area for closer examination.

Health

Strain
4 of our questions dealt with injuries from strain. The result shows that this is twice as usual as in the population as a whole.

Table 3
Injuries caused by strain, group A and B

	yes	no	%%	%% in the population aged between 70 and 79
Injured feet	9	32	22	11
legs	11	30	27	-
back	11	32	26	13
rheumatism, gout	9	29	24	20

The high amount of injuries could be caused by the positions used when working so that the joints are strained. Another explanation is that the deaf-blind are in bad physical shape so that their muscles cannot cope with strain. To find out more about health and physical

fitness we asked 5 questions. Difficulty in breathing is twenty times more common amongst the deaf-blind than amongst the rest of the population between 70 and 79. To little exercise seems to be an important reason why the deaf-blind suffer more injuries from strain. They also suffer more from headaches, dizziness and trouble with their sleep than others.

Table 4

Variables in connection with health and fitness, group A and B

	yes	no	%	% in the population aged between 70 and 79
Trouble breathing	12	30	29	2
Cough	10	30	25	-
Headache	9	29	24	5
Dizziness	7	32	18	12
Trouble sleeping	14	28	33	5

Table 3 and 4 show that the health of the norwegian deaf-blind is bad. It seems to prove that the high amount of injuries from strain is caused by the little exercise shown in the trouble many have with breathing. Headaches and trouble sleeping indicate tensions and faulty positions when working. These tensions may of course have mental causes. Apart from the problems already mentioned, four times as many Deaf-blind persons have trouble urinating and defaecating than the rest of the population.

Mental health

To find out what the state of mental health is among the deaf-blind, we have asked about feelings of depression and dejection. These feelings showed themselves to be very common. 1 out of 3 suffered from them. We have looked at the differences between group A and B.

Table 5	yes	no	%
depression, dejection	14	27	34 (group A and B)

1 of 3 suffer from these feelings.

Group A: 9 23 28

1 out of four suffer from depression/ dejection

Group B: 5 4 56

Out of the five who answer yes in group B , four live in an institution. Table 5 shows that fewer of those in group A feel depressed and dejected than in group B. In group A 1 out of 4 suffer from these feelings, a very high figure. In group B, the small amount of answers show that more than half feel depressed and dejected. In group B 4 of the 5 who answered yes live in institutions. If we look at those who feel depressed in group A we find that it is more common to feel depressed/ dejected amongst those that are married or living together with someone. 5 out of 8 of those feel depressed but only 2 of 3 of those who live alone. This is unexpected and interesting.

Table 6
Depression, dejection, headache

		Married/living together	Living alone
Depression	yes	5	4
	no	8	10
Headache	yes	3	6
	no	11	9

The table shows that depression is more common among the married and those that live together with someone. Even if the number interviewed is small, this is interesting since it is unexpected. The possible explanations are many. One is that deaf-blind people who live on their own have more control over their lives. They can plan their lives so that they are seldom reminded of their handicap. Those that live with

someone will be reminded of their handicap more often. Another explanation is that you become more passive when you live with someone, and that you have more time to sit and think. This also means that you have less control over your life. If you are often helped by those you live with this also serves as a reminder of your handicap, as does the fact that visitors perhaps talk with the people you live with, excluding the one who is handicapped. The deaf-blind who live alone spend a lot of their time on cooking, cleaning and so on. Another fact that supports the theory that lack of control leads to depression is the fact that it is very usual among those living in an institution (group B). In the second part of table 6 we see that headaches are more frequent among those who live alone - 2 out of 3 have them, while only 1 of 5 among those who live with someone have headaches. This could be an indication that the strain on those who live alone is bigger and that they are far more tense. It could also indicate that those who live with someone have other ways of solving their problems than do those that live alone.

Exercise

1 out of 4 never exercise. 1 of 4 walk more than half a mile every day. 1 of 4 exercise in more organized forms, they swim or go to gym classes. Many have exercycles, but few use them. 3 out of 4 exercise a little every day. Some of them did light training.

Methods of communication

Most deaf-blind use more than one method, mostly a combination of sign language and manual alphabet. This goes for about 50 % of the deaf-blind, while only 1 of 10 use sign language exclusively. This indicates that many of the deaf-blind use two methods of communication to be sure that they comprehend what is being said. This is an important piece of information for all professionals. In this way the deaf-blind differ from other groups, like the deaf.

Conclusion

Important to note in our survey is the low amount of answers we received from group B. It tells us that we know little of the group, that does not avail itself of the services offered the deaf-blind community. This argues for a decentralisation of our work.

Contact person, adjustment courses and the interpreter service has improved the quality of life of deaf-blind people. Especially the answers to our questions about contact persons have been very clear. When it comes to to the adjustment courses, the picture is not quite as clear. This is due to the fact that some attend the courses several times, while others never attend them. This, we feel, indicates that we should work harder with information and motivation.

We are only just building the interpreter service, but even though this means that there are still problems to solve, our survey shows that the interpreters are very much in use, especially by those who live alone, and do not have a husband or a wife to help them. To them, it is of very great importance that we continue building this service.

Many of the deaf-blind use special news service. Our survey shows that the deaf-blind seek their information where they may find it, for instance in papers and on TV. The news service is of special importance, since it is available on cassette, in Braille and in large print. That the deaf-blind seek their information where they may find it shows that they seek it actively, in spite of the fact that it is difficult for them to assimilate it.

Looking at the social network, the surprisingly high number of 1 out of every 3 deaf-blind people do not have daily contact with other than their home help. This, of course, makes for greater isolation and make the contact person or interpreter very important. In this context it is also essential to work for decentralised services. In Oslo, for instance, there is a "social environment worker" who visit the deaf-blind in the region.

As to health, the amount of injuries due to strain is surprisingly high, and there are many indications of to little exercise and bad physical

condition in the group. The injuries and the bad condition are perhaps connected, but the injuries may also have economical causes. The deaf-blind community as a whole seem to get to little exercise. Those who have a public bath in the vicinity use it, but very few go for outdoor walks. It is important to encourage the deaf-blind to get more exercise of one form or another, if the general health of the group is to improve.

We found that feelings of depression and dejection are very common in the group. Many of those in group B who suffered from these feelings live in institutions. Unexpectedly, those that are married or living with someone more often feel depressed than those who live alone. This leads to the conclusion that the handicap itself is a great strain. This is to be expected. We also expected those who live in institutions to feel depressed more often. What we did not expect to find was that those who are married are more often depressed than those who live alone. A possible explanation is that those who live together with someone have less control over their own lives, they are more often reminded of their handicap and they are more passive. Lack of control over your life causes depressions, whether you are deaf-blind or not. All those who live in institutions have little control and risk becoming depressed. Very important are the things we found out about the health of this group. This is new information, and it is also unexpected. We have very few tools when it comes to finding out how the deaf-blind individual feels, and most of the measures we take are based on our ideas about what could be of gain to the deaf-blind community as a whole. One of our most important tasks is to ways of finding out what the individual needs and then to help by finding the aids and other measures to fill those needs.

Report from the Soviet Union

"Teaching Braille to deaf-blind children with the help of technical aids", G. N. Bespalov and L. F. Obuhova

The reserach presented in this paper was carried out in a dissertation a number of years ago at the Defectology Institute . Nowadays, the technical side of it might seem a little primitive and even amateurish, but the psychological and pedagogical principles underlying the research deserve attention.

The investigation is devoted to the use of a specially designed technical aids system in teaching Braille to children who according to conventional criteria are considered deaf-blind. (A child is considered deaf-blind if she or he cannot attend either a school for the blind, nor for the deaf. Residual sight in such a child would not allow it to read ink print.) No doubt it is unnecessary to specially underline the fact that writing and reading Braille expands the communication possibilities of the deaf-blind, contributes to the growth and perfection of their verbalized speech without which full valuable mental development of the most heavily disabled children is unthinkable.

Teaching Braille to the blind and the deaf-blind consumes time and labour. It usually demands wide use of various instruction aids and devices (a Braille frame, a plate with Braille symbols, a Braille cube, a writing device, and so on), which allows perception of the Braille letters only by way of touch. When working with such devices it is difficult and sometimes impossible to make use of residual sight. Writing on a typewriter, which the deaf-blind usually like, soon causes fatigue for pressing keys demand a great deal of physical effort. And it is also based on touch. When pressing keys, children do not notice their mistakes. They can check the writing only after the letter has already been typed. Due to the weak muscular effort, letters are being illegibly typed, whereas checking what has been written demands adequate discrimination of the points in a Braille symbol, and this is possible only if the touch is well developed.

Using technical aids which provide feed-back and encouragement when learning Braille makes the process of instruction more effective.

Special devices allow the deaf-blind receive information both with the help of touch and with residual eyesight.

The whole process of teaching was divided into a number of stages. At the first stage, when the deaf-blind child was introduced to Braille, a visual training aid for space orientation was used. Its main purpose was to form concepts of space relationships: top, bottom, right, left. The device consists of two parts: the first one is used to construct a sample (pattern), and the second is used by the child to solve a task. On the panel of each part on this device there are 5 lamps and 4 square holes for cubes to be fixed in. If the child has performed the action adequately, according to the pattern, the lamps on his part of the device light up. This device helps the child orientate within a limited space, as within a sheet of paper, and within it distinguish interrelated locations and the quantity of objects. This is an important condition for learning Braille, where each sign represents a complicated combination of points, everyone of which has its own place.

At the second stage of instruction, the children get acquainted with images of Braille symbols with the help of a visual Braille six points frame. In this apparatus the presence of a raised point is represented by a lamp, and the absence of a point by the absence of the lamp. The device has a panel consisting of two parts set at an angle to each other. Each panel in turn has six sockets, like the six points of Braille. The child percieves the configuration of lamps on the horizontal panel with the help of touch and residual eyesight, and must then fix in the lamps on his sloping panel in the same configuration. An adequate solution of this task lights up the lamps on the sloping panel. The child performs this task with the help of direct demonstration, a pattern or a tactile sign.

The next device – a visual Braille line – allows the child to learn letters, words and sentences in Braille.

The third stage of instruction is aimed at forming elements of writing with the help of a visual Braille training aids system. The purpose of the first one in this series of aids is to help the child learn the correlation between the keys of a typewriter used by the blind and the appropriate point in a Braille symbol. The device has a key board with six keys, similar to the typewriters used by the blind, and a tableau with six

lamps. The lamps are set on two planks which can be fixed horizontally or vertically. If the planks are set horizontally, it means that each key is opposed by an appropriate lamp. This makes it easy for the deaf-blind child to understand the link between the key which is pressed and the lamp that lights up as a result of that action. With a teachers help the child can change the horizontal set of the planks to a vertical one, which means that the lamps constitute a Braille six point frame.

The next apparatus of this series has an additional key which allows you to fix a Braille symbol on a light tableau. In order to organize joint work of two pupils the design was additionally modified; the light tableau changed its position in relation to its vertical axis. It could be turned away from the child performing the action towards the one checking it.

The most important stage of teaching Braille to the deaf-blind with the help of special technical aids, is the formation of tactile images of Braille symbols. At the very beginning of instruction a deaf-blind child cannot in practice percieve the signs produced by a Braille typewriter, for the symbols are too small, and proper discrimination is not yet developed. To develop that, it is necessary to do a lot of preliminary exercises. In the research in question, when working with a visual Braille six points frame (VBSP), the children at first developed visual images of Braille symbols using rather large patterns (60x30 mm). The size of six points on a Braille training aid was cut to 40x20 mm. Switching over to tactile perception of the signs printed on a typewriter demands that a number of new devices are designed to facilitate the process.

A tactile-visual Braille training aid consists of a key-board with seven keys. The upper panel of the board has a right angled removable plate with six holes for lamps. On pressing the keys, the lamps protrude and light up, thus constituting a raised sign measuring 30x1x15 mm. The device also has an additional plate with a frame of smaller points, 20x10mm. To further diminish the size of the symbol, there are two electrical, mechanical tactors attached to the device with Braille signs measuring 10x5 mm and 6x3 mm.

In this way, the ability to read standard six point Braille was gradually formed in the child.

At the last stage of instruction, the possibility of using electric typewriters to more effectively form writing skills was investigated. A controller-indicator set was designed to be added to a Piht's typewriter especially for the deaf-blind with little residual eyesight. It allowed children to control their work while writing, and they could correct mistakes before the raised points appeared on the paper. A light touch on the keys light up a Braille on the tableau added to the typewriter, and the child can check if any mistakes have been made. In case of an error, the child changes the combination of keys pressed before finally typing the sign.

This technical aids system makes the work less tiring for the pupils, enhances their interest in learning, shorten the time spent on mastering Braille, sees to it that the children cooperate while learning and significantly facilitates the work of the teachers.

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Report from the Soviet Union

"We were entering upon contact together", Natalia Krylatova

The primary communication between a mother and a new-born child appears in the course of their first contacts, which consists of the care from the mother's side and the child's reaction to the care. Such a traditional order has existed during thousands of years, and there is an illusion that this communication is born spontaneously.

But I am a deaf-blind person and have no such illusion, because I can understand people by means of either the Rus- sian manual alphabet (dactylology), or Braille, and both these methods demands literacy in my intelocutors, which certainly is out of the question with a new-born child, even a healthy one. That is why just from the very beginning I had no hope that any kind of communication would be formed spontaneously; on the contrary, it was absolutely clear that all the necessary communication might be built only as a result of my own active efforts. But how could I make the communication possible? That was the most difficult problem for me when I was going to become a mother. At the same time my own independence in taking care of my baby was obviously important.

Considering this, I had to refuse all my friends who wanted to help me in taking care of my new-born daughter from the very moment of returning home from the maternity clinic. Such a desperate decision certainly led me into all the inevitable difficulties typical for all blind mothers, and even worse because of my deafness. But at the same time there can be no doubt that any other way out would only have led to more difficulties, and no method for communication could have been found at all. In short, I had come up against the necessity of trying to find a non-traditional way of finding out how my baby was. I hoped I could do this.

A blind mother can hear the baby crying, breathing, laughing etc. A deaf mother can see the expression on the face of her child. I can do neither. But it is nevertheless wrong to think that there is nothing I can do, for there are some things which are possible for me to find out. If,

for instance, my little daughter is hot, I can easily feel her wet face and hands and I can feel her tossing about. While stroking, caressing and kissing my little baby I could always learn many things about her. And thus, little by little, I succeeded in accumulating experience in communicating with the girl. Simultaneously she was also learning how to express her emotions in a more or less understandable way. After a while, the baby needed more and more to be in touch with her mummy, and out of that our communication grew.

I often used to play different baby games with my daughter, such as "the goat", "hide-and-seek", "the cuckoo" etc. I learned from her merry laughing that she enjoyed those games greatly. On day I felt the girl attempting to imitate a movement I usually used while playing. I tried immediately to reward her for this attempt by more playing. The girl liked it very much and started using the same movement each time she wanted to renew the game. That was the first signal my daughter made up herself to communicate with me, but it was not the last one, and soon we had a rather developed "language" to use when talking together.

Here is one more example. The girl wants to make me play the game "clap-clap, rabbits cap", so she takes my hands and makes them clap. At this moment she is evidently waiting for me to recite the verse which is the only part of the game she cannot perform herself. So I begin reciting, and now she leaves my hands free and starts clapping her own hands with apparent joy. It was in this way that our special "language" developed.

Yet we clearly realized that if kept up this "primitive" communication we risked getting into a deadlock, from which there would be no natural way to achieve a more or less literate mode of communication. This is a problem often met with in the traditional education of the deaf. The sign language (especially a self-made one) cannot in a natural way develop into a verbal one. This we have learned from numerous examples, such as the life of Helen Keller who used to speak to her childhood friend Marta Washington with the help of home-made signs. It was painful for her to take the step towards even the single word "WATER". Keeping in mind the painful shift from sign language to a

verbal language based on the alphabet, we started preparing this shift before the child was to old. The preparations consisted of helping the child to recognize the Russian letters (both in print and the manual alphabet) and to reproduce them with her fingers. All this work was done through playing a series of special games designed to train the fingers to reproduce the letters. We did this in the form of games so that the training process would be more attractive to the child. We can now say that all the work was successful, and that by the age of one our daughter had mastered almost all the letters of the Russian alphabet.

But knowing the letters does nor necessarily mean that you are able to use them to communicate. It is, moreover, difficult for a baby to understand the relation between letters and talking, and it was very hard for her to start using letters when talking to mummy.

Having discovered the important function of the letters, the girl soon began to reproduce the first letter of the word she wanted to say to mummy, who managed to guess the whole word according to the situation. This kind of communication was of course not perfect, but it had the undoubtful advantage of further developing the verbal communication. We soon became convinced about this. After a certain practice, Hilda herself discovered that there are many words in Russian that begin with the same letter. We were waiting for that discovery and had prepared a batch of cards and a box of fibre tip pens to write to words with, so that the cards could be shown to her when she needed help. Her father prepared these things for Hilda to help her with the finger spelling. To our great joy the girl willingly took the cards and tried to reproduce words according to them. She quickly understood the advantages of the batch of cards which we later called "Hilda's Crib-Encyclopedia". She liked her "cribs" and used to hide them in one of her secret places where she could find them when she needed them.

The period of the "Crib-Encyclopedia" lasted about a year. During this time Hilda learned to reproduce some simple words without consulting her "cribs", for she had understood the way in which the finger letters followed one another, and she even managed to construct a few words missing among the "cribs" without help, and make her mother understand these words in spite of mistakes in spelling. By the age of three

and a half Hilda could already, more or less easily, tell her mother whatever she wanted. Her spelling of course often differed much from traditional orthography, but together we had stepped across the threshold of early literacy.

I can add that nowadays my eldest daughter Hilda is six years old. She speaks to me in the Russian manual alphabet as well as any grown-up, and there are few mistakes in her spelling. Hilda attends a good primary school in Moscow, and her teacher speaks well of her.

I also have a younger daughter called Dina. She is five years old. Dina is also able to say whatever she wants to me, and we have no communication problems. Our family has the same problems as any other family. I think I dare say that I am as happy as a mother can be.

Report from the Soviet Union

"The problem of communication and classification of the deaf-blind", Elena Shakenova

Our section for social rehabilitation of deaf-blind persons pays great attention to the problem of communication. It was natural that our first manual edited for the social workers of the All-Russian Association of the Blind was called "How to communicate with deaf-blind persons". Maybe only skilled professionals who have worked with the deaf-blind for many years know well that the deaf-blind population is heterogenous not only not only in their means of communication but also when it comes to perceiving and understanding information. They not that the primarily deaf (group 3 according to the Nordic classification of the deaf-blind) are sign-speaking, using signs mainly to communicate. The primarily blind persons (groups 3 and 4) are so to speak mainly verbal, and have good understanding of the manual alphabet and Braille. There are also people who are born deaf-blind (group 1) who have very little ability to understand any information, either in usual or sign language. All these differencies depend on the age at which a person became blind or, especially, deaf. In addition to the Nordic classification we offered in our booklet "How to communicate with deaf-blind persons" a classification of deaf-blind people according to their speech development and means of communication.
1) The verbal group, or "verbalists", who use normal speech in any form (manual alphabet, Braille, spoken language etc.); consisting mainly of the primarily blind.
2) The "sign-speaking" group, or "signers", using signs as their main language.
3) The "mute" group, who have practically no speech at all.

So the problems of social work in these various groups are different and to solve the problems you must know the specific character of each group. This is an important thing often unknown to the people surrounding a deaf-blind person, and even to their relatives or fellow employees. Very often the difficulties of communicating with deaf-blind people are thought to be caused by mental retardation or defects. Sometimes the characteristics of mentally retarded deaf-blind persons are ascribed to all the deaf-blind. Such an erraneous estimation is often taken to heart by deaf-blind people as it is a social injustice.

This is why our section pays great attention to information about the deaf-blind, mainly directed to the people surrounding them. To this purpose we have published two manuals: "How to communicate with deaf-blind persons" (1986) and "The deaf-blind. A social and psychological characteristic of the population" (1987). They will be translated into English for our foreign colleagues.

We make careful studies of the experience of social work with deaf-blind persons; of communication and information for the deaf-blind in different countries. It was very interesting and useful to study the data concerning social work with the deaf-blind and their lives in Nordic countries, USA and England. Unfortunately this information is very irregular.

A regular exchange of information concerning the problem of deaf-blindness is valuable and necessary, not only because it is a matter of interest, but also beacuse we need propaganda for a differentiated approach towards the deaf-blind population. Problems of communication and information among the "sign-speaking" deaf-blind are of special interest to us. They are deaf-blind people with normal intellects and psychology. The problems of their speech development are not connected wit their "defectiveness" or their poor vocabulary, as some people, even some scientists, believe. Their way of thinking is formed under the influence of a sign-speaking environment due to their early deafness. Such a way of thinking is consolidated in the course of their lives preventing them from an adequate perception of speech, even if their vocabulary is rich. This is of course partly connected with the faults in our speech training. We must find more effective speech training methods for the deaf-blind who are primarily deaf. Any research or experimental work in this field is useful.

Unfortunately our scientists prefer research and experimental work with totally deaf-blind children. This means that adult sign-speaking deaf-blind persons, for whom the most favourable period for education is "lost", do not get attention from scientists. More than that, scientists only regard those that are completely deaf-blind since early childhood as deaf-blind (group 1 of the Nordic classification). They pay no attention to other deaf-blind groups. Sometimes all the deaf-blind are regarded as totally deaf and blind. In this way the differences in their personal development are ignored, consciously or unconsciously.

There are for instance some deaf-blind persons who have lost their hearing late in life and who preserve oral speech. Scientists often regard all the deaf-blind as one group and make no difference between those who become deaf-blind late in life on one hand and those that are born deaf-blind or become deaf-blind in their infancy on the other. Those who become deaf-blind late in life are presented as people who were taught to use oral speech. Their acheivements in education and and their speech development are said to be the result of special education, a kind of scientific sensation.

Sergei Sirotkin and I entered upon polemics with these scientists (A. N. Leontev, A. I. Meshcheryakov, E. V. Ilenkov, V. V. Davydov and others). We organized a number of scientific discussions on different aspects of the problem of deaf-blindness with the participation of leading philosophers, psychologists and teachers at special schools. Material from the discussions were published in some special magazines and in a booklet, "Deaf-blindness. Historical and methodological aspects of the problem. Myths and reality." (1989, edited by the Soviet Society of Philosophy). The main aim of our discussions was to show the necessity of a differentiated approach to deaf-blind people, both in practice and in scientific work. Without such a differentiated approach any effort to solve the problems of the deaf-blind will only end in deadlock and the work with the deaf-blind will be incorrectly organized. This approach is the only way to solve the problems of communication for the deaf-blind that use sign language. We decided to devote ourselves to such work, including the problem of adapting literature (information) for the deaf-blind who mainly use sign language. It seems that there were no scientists engaged in the special problem of adapting literature for them. The difficulty of this problem is connected with the fact that sign language has no written form, unlike the spoken language. This is why we must find methods to adapt ordinary verbal texts to the thinking of of the people to whom sign language is the main language. This of course does not mean that these deaf-blind should abandon any attempts to develop normal speech (verbal language). Normal speech development is possible during the course of special education, but it is very difficult to organize such education for all the deaf-blind. It would be wrong to abandon the problem of adapting texts for those that use sign language, saying that signs "damage" the speech development of the deaf-blind. Our approach to this problem must

be realistic. As long as "sign-speaking" persons exist, the problem of communication will exist also.

Perhaps the problem will be solved partly with the help of adapted texts, as if for children, using the language of children's books to describe adult problems. We must study expressions that are in common use in sign language, even "incorrect" ones, and use such expressions in the composition of adapted texts for the deaf-blind. We now attempt to produce information with adapted texts for those that use sign language.

This is only one aspect of the problem of communication that we are trying to solve.

I must repeat that we feel that we lack experience and information concerning the problem of social work with deaf-blind adults. International cooperation is necessary here. So we call upon all the professionals who work with the deaf-blind and upon all the people helping the deaf-blind in all countries just to exchange scientific information and to develop international cooperation in the field of social rehabilitation of the deaf-blind and to organize the international cooperation of the deaf-blind people themselves.

Report from the Soviet Union

"Problems of the developing service for the deaf-blind",
Leonid Shavelson

For quite understandable reasons the life of a deaf-blind person is inevitably connected with service yet without self-dependent, active, creative and socially meaningful activities on his part it can not be adequate. How can this contradiction be solved?

The first issue is the attitude of the deaf-blind person towards his misfortune. To be able to regard himself as a human being first of all, and an invalid only secondly, he is largely dependent on the moral standards of the people who surround him. This attitude to life is a necessary condition for work involved with the creation of such a system of services which would naturally develop into a system of self-services in cases where it is possible. The greater the independence of the deaf-blind person, the less he depends on others and this makes him free. His road to freedom lies in developing services.

Already at the stage when the deaf-blind person masters the culture of everyday life, work with him can be conducted in two opposite directions; the development of the habit and skills in manipulating objects, or the development of a notion about an object and its purpose (through an assimilation of the superficial scheme of actions and a direct involvement in the practical situation). He can for instance be taught how to merely drag a broom around the room, like a performing bear at the circus, or he can be taught to precisely sweep up the dust with the broom. Here the whole point is not only in the opposite practical results of these two actions; scattered litter or a clean floor. First of all, in both instances a personality of a certain type is built up. What happens in the first case is that a person who is already limited in his potential is further confused, while in the second case you have created a basis for the development of an independently thinking person. This person will be able to cope with his difficulties creatively, and to create his own system of self-service.

These two ways are observed in spiritual sphere too; in satisfying the spiritual requirements of the deaf-blind person it is only to easy to

reduce everything to the organizing his his amusements and light entertainment, thus securing a mindless existence for him. One of the consequences of this way of life is a consumptive attitude to spiritual values. Therefore, we must always bear in mind that a deaf-blind person can achieve true social rehabilitation only through personality development of the highest order.

Nevertheless, it is not only thoughtless service and idleness in leisure time that leads to the formation of a consumptive style of living. Not less important are certain methods of teaching deaf-blind people. We encountered this phenomenon in 1970 when we began to prepare our deaf-blind charges from the Zagorsk Children's Home for joining the Lomonosov Moscow University. Only one person out of four accepted the problem methods of learning without difficulty. The others were quite content to deal with knowledge in the form of a summation of information data, which replenished their erudition. With them, problem situations did not serve as basic points for the development of ideas, they merely irritated them. This was in many things determined by the history of their personality development, the style of communication with their friends and relatives and the character of their previous learning.

Today they operate as scientific workers and life makes great demands on them without making allowances for their deaf-blindness. Creative scientific activities puts the problem of services on a new level. Fruitful ideas do not fall from the skies, they are a result of enormous practical work and the profound interested comprehension by the person of his own activities and the activities of other people. Along with the fact that the deaf-blind person must be trained and prepared for real creative work both in everyday-life and in academic spheres, he must be given the chance to work independently for some time to completely accomplish all that he still cannot do well enough. He should be inspired by ideas, which are in keeping with his own spiritual make-up so that he can assimilate them as his own and be guided by them. He should be able to critically transform these ideas and, in the long run, generate something new. It is very important here to involve the deaf-blind person in the entire scope of vital doings and contradictions and to have faith in him as in any creative worker.

We consider it expedient, along with the existing category of pedagogical style, to introduce the concept of a style of services, which at all stages of development of the deaf-blind person determines his attitude to himself and to other people, since this in the long run determines his fate. The more profoundly will the deaf-blind person understand other people, the wider will the field of his social vision be and the easier it will be for him to participate in full-blooded activities and rise to the apex of of personality development. And vice versa; the more thoughtless the satisfaction of the deaf-blind persons requirements, the greater the risk for the formation of extreme forms of individualism, which inevitably lead to loneliness and, consequently, to degradation and loss of accumulated spiritual riches by reason of their being unclaimed.

In this way developing services is of permanent importance throughout the entire life of the deaf-blind person.

Report from the Soviet Union

"The deaf-blind person and people with normal vision and hearing", Alexander Suvorov

The question concerning the attitude of the deaf-blind towards both people with normal vision and hearing and absolute strangers is a cardinal one, and for the deaf-blind it is verily a question of life and death. It is not so much a question of this or that method of communication as of this or that orientation of the personality of the deaf-blind person. The most important thing here is the stand he himself takes - that of dependence or that of cooperation. On this his mode of life depends - the life of an invalid who, consciously or unconsciously, isolates himself from everybody, or a full life which makes it possible for the deaf-blind person to take part in the life of society and humanity in general and which makes him, like any other normal person, a full-fledged member of different groups.

When children meet only adults and other deaf-blind children (in special institutions), they do not realize their own limitations; limitations caused by their deafness and blindness, and therefore they do not aim to overcome them. They are just not aware of their limitations. Adults represent a standard or model and like all models they are never subject to comparisons. The other children are also disabled. As a rule they do not come into contact with healthy children due to the efforts of compassionate adults, who believe in the myth of children's cruelty. In this way, all conditions exist to make the child in a special institution consider his blindness and deafness a normal state.

But this is an illusion! And when the illusion that blindness and deafness is normal collides with everyday life and is dispelled, the consequences can be very serious. For instance, the myth of the existence of two hostile worlds - "the world of the deaf-blind" and "the world of people who can see and hear" - can emerge. This myth leads to deliberate isolation from the "enemies", who can see and speak. The child isolates itself from everybody, but two or three people, who, by way of exception, turned out (or claimed) to be "friends" or "saviours". In this way the deaf-blind person becomes blind and deaf not only physically, but spiritually too.

We have come to the conclusion that the nightmare of spiritual blindness and deafness can be avoided only with the help of one method; special organization of communication between deaf-blind children and those who see and speak. And if we propose to let our charges out into the "seeing and hearing world (and there just is no other world for them to live in, for one cannot regard the psychoneurological boarding-house to be the "other world"), then we should teach them to live in this world, and the earlier we do it the better. They can learn the art of living only through communication with children who see and hear, and as they are also children the deaf-blind child will, naturally, compare himself with them and, as they can see and speak, he will inevitably come up against his disability all the time and be forced to realize it. Serious work with children who can see and hear (or more broadly, children who may be blind but who has normal hearing) is called for. Their attitude to deaf-blind children should be built up by their mentors.

And then the disabled child, having become aware of his limitation, will want to overcome it, and thus becomes our most loyal ally and associate in the difficult task of surmounting it. In his communication with children with normal hearing he will, willy-nilly, have to use the national verbal language in its oral and written form. In time he will gain the incentive to master the greatest number of communication means possible. When he grows up he must be able to communicate with his neighbours, his colleagues and passers-by. This is certainly no easy matter, and everything is, of course, highly individual, yet we expect precisely these aforementioned results from joint pedagogics and joint education of deaf-blind children and children with normal hearing.

The theory and practice of joint pedagogics is only in their beginnings in the USSR. The first man to work in this field and organize it was the former director of Zagorsk boarding school for deaf-blind children, A. V. Apraushev. He invited children from the neighbouring school to visit the children's home, but at that time (the middle sixties) the attempt to create some sort of communication between these two groups of children failed. In 1980 a pedagogical enterprise, "Rainbow", began to function. Students and children from senior grades work here. Their main assistance to the children's home is in connection with housekeeping and they drew the inmates of the children's home into these activities. The "Rainbow" organized hikes and festivals for the children,

and later the employees began to teach the children to play games and to use computers.

Today scientific workers of the Research Institute of General and Pedagogical Psychology of the USSR Academy of Pedagogical Sciences work on the organization of joint pedagogics. This work is conducted under the guidance of the Candidate of Sciences (Psychology), Assistant Professor of the Moscow University, L. F. Obukhova. The organizers and coordinators of the work are A. V. Suvorov and L. D. Shavelson. We have already managed to take our children to a pioneer camp of the usual kind called "Salute", which is located in the Leningrad region. In 1988 four inmates of the children's home lived there (two of them were attached to one Young Pioneer detachment and the other pair to another detachment). Already in August 1989 we brought 8 children and they formed a special detachment. In spite of this organizational isolation, the contacts of our children with those with vision and hearing were many. The special detachment even contributed to the creation of a free and easy atmosphere and of general goodwill.

For two years now the district headquarters of the House of Young Pioneers of the Babushinsky Region of Moscow has worked in the children's home. On the initiative of the leader of the headquarters. M. N. Osinovsky, the Zagorsk children's home has become the concern of the most active pioneers. A special pioneer detachment, "Contact", which includes children of different ages, has been organized at the House of Pioneers. The children know the manual alphabet and learn the Lorma code, modified for the Russian language by N. N. and Y. D. Krylatov (both husband and wife are employees of our Institute; N. N. Krylatova is deaf-blind). Besides taking part in joint festivals and hikes, our pioneer detachment organizes joint excursions.

Cooperation with the Moscow School No. 1 for blind children and children with poor vision, whence we sent a blind boy with poor hearing, is also expanding.

Joint pedagogics envisages the inclusion of disabled children into the world of healthy people. At present, disabled adults find their way into it on their own. With me, joint pedagogical activities is the main opportunity to participate in the life of the great world. Another opportunity is

my literary creativity. I write topical articles and poetry, and this is my main occupation.

There also exists another opportunity. It is everyday life and relations with people who surround me. This opportunity is in many things determined by the social quality and scope of ones personality and to what extent people need one and in precisely which capacity one is particularly necessary to people. The more I switched to concrete doings and practical activities, leaving behind my theoretical studies and lyrical verse, the more colleagues-friends I found, the more organized did my everyday life become, even against my will. For many years now I never have to go to Zagorsk alone, there is always somebody who is willing to accompany me to Zagorsk, to the Institute and even to the shops. I must say that people help me without expecting to be paid for it and they do it with a will.

But there was a time when I lived alone. I walked and rode in buses and trains always alone. The "seeing and hearing" creators of the surrounding civilized world gave no thought to the deaf-blind or to disabled people in general. They did not rely on them, but then they did not rely on themselves overmuch either. When building roads they chiefly considered the needs of the traffic. It is very convenient for a blind person to use the narrow concrete sidewalks, but it was not of the blind that the roadbuilders were thinking, but about the clean shoes of the pedestrians. And creating self-service shops, which are also convenient for blind people, the constructor most likely reckoned with the economies in the wages of shop-assistants this service would bring with it.

What I mean to say is that it is very difficult for deaf-blind people or disabled people in general to live independently in the world of healthy people. The former cannot cope with life without the help of healthy people and this means that he must have contact with them. I long ago formulated the rather harsh conclusion that the world of those who see and hear is alien to the deaf-blind. I do not at all mean that this world is hostile towards him, it is just very difficult to live in it because he does not adapt to the lack of sight and hearing.

But alien as this world may be, there just isn't any other for the disabled person to live in and he can survive in it only with the help of people, and not the same people all the time, but casual, different people all the time. He should organize his help himself, he must know how to ask for help, without at the same time abusing himself. It is not enough to master the most widely spread means of communication (verbal language in all its possible forms, particularly in the form of oral speech and writing on the palm). He must know how to come up to a stranger and how to ask for his help without scaring off the potential helper.

In other words, it is either a vegetative life in some reservation for the disabled, or the compensation of any physical defect by personal integrity. That is the way it is in all things, be they of universal character or everyday trifles.

In the years of my forced independence in order to survive I organized the help of people who surrounded me (they were frequently ordinary passers-by). With this aim in view I developed a system of devices of appeal for help, and devices directed towards drawing people's attention to my person. This system was based on the file of assistance.

I prepared the cards myself. Very briefly, according to Braille, I designated the content of the request by letters and figures and then, using the Braille designation, I typed it on an ordinary typewriter. Two cards were universal (with instructions how to "talk" with me by means of writing on the palm of my hand). Another card was an identification card with my first name, surname, home address and the phone number of my neighbours on it. I also prepared about thirty cards with concrete requests for recurring situations. All these cards began with the words: "Comrade, I am blind and deaf". The universal cards were designated "Speech card" and "Speech card for music" in Braille. Both cards bore the instructions to write the message on my palm, but the second card had an additional statement, which said that I possessed residual hearing, which was sufficient for the perception of music (with a hearing aid), but not for speech. I used the "Speech card for music" when I bought tickets for the ballet.

The names of the cards speak for themselves, for example "Hairdresser", "Any food, which is available", "Breakfast", "Dinner", "Supper",

"Ticket for the public baths". I made very many transport cards bearing the request to put me on a certain bus or trolley (here only the numbers were written in Braille), or on a train with the name of the terminal which was my destination. On the cards, which held the request to help me out at a certain stop, the name of the place was given in Braille. The card "Taxi" was intended for the most difficult situations. Nevertheless, it is impossible to foresee all situations, so along with my permanent cards I used cards meant for one occasion. For example, before going to the shop I would write a list of the goods I needed. Naturally, it followed the usual message about me being blind and deaf. Then the shop-assistant, administrator or another customer would help me to buy the things mentioned in my list.

On my request a friend made me a little placard on which the following words were embroidered in black thread on a white background: "I am blind and deaf, I need help". Underneath this message the international sign "SOS" was embroidered in red thread. Between these two inscriptions a vividly red cross was sewn on. The placard had long pockets for sticks on its top and bottom – I held the upper stick in my hand while the lower stick kept the placard from rolling up. When I did not need the placard it lay in my pocket, but in difficult moments I could immediately take it out of the pocket and unroll it. Seeing the placard, people would come up to me and I would hand them the necessary card. By and large this mechanism worked, though sometimes people would take me for a beggar and give me a few coins. Sometimes worse things happened. I a dense crowd nobody paid much attention to me and my cane. A number of times I was knocked down and people, stumbling over my cane, broke it. For this, I called the people in the crowd "blind seeing ones", and in order to help them recover their sight I would begin to blow a sports-whistle for all I was worth. It had the effect needed: at first people would dash aside, but in a minute or two somebody would without fail come over to me and ask "Can I help you? Where are you going?" I was not embarassed by the fact that some people would think me crazy. Let the man in the street imagine anything he wished, the thing was that my ribs and cane were left intact.

Since 1988 pocket identification plates are sold in our country. One side of the plate bears the following inscription: "This man is deaf-blind". It is followed by instructions for communication – to show the

necessary letters in Braille (next to each Braille letter stands a letter in the ordinary alphabet). On the other side of the plate is an inscription which reads: "This deaf man has poor sight". Here the usual alphabet is presented in very large letters and it is followed by the same instructions as on the Braille side. The characters are clear and vivid and set against a contrasting background. When sometimes I walk alone, which happens very rarely now, I always have this plate with me. The plate immediately attracts attention, all the inscriptions can be read at a "safe" distance and the formal factory-made appearance inspires trust and convinces people that the bearer is indeed deaf-blind and not a madman, a beggar or a spy. But the skipping from one letter to another, according to the instructions, takes a long time and is, in general, an awkward task. I, therefore, immediately suggest that the person writes his message on my palm in large letters, as they are presented on the side of the plate intended for people with poor sight.

However, after the showing on Central Television of the film "At a Touch", produced by A. Arlauskas and myself, people recognize me in the street and write messages on my palm without any instructions from me. While people remember the film I can do without identification plats and other devices. But they are already beginning to forget the film.....

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An account of the newly established New Zealand Society for Vision and Hearing Impaired, how it is organized and it's goals for the future.

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Rajinder Singh Sethi, India

No surveys have been carried out in India to ascertain the number of the deaf-blind population, so very little is known about methods of communication. This is a personal report on the experiences of Rajinder Singh Sethi.

On my own experience of communication
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An account of the personal experiences of Sergei Sirotkin, who became deaf-blind at about the age of six, of how he learnt to communicate, and his subsequent education, and the work that he has since done for the deaf-blind.

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An account of the work and the goals of the only school for deaf-blind children in India, and a summary of the school curriculum.

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A personal account of the life of a deaf-blind girl in Brazil, and of her struggle to find a way out of loneliness and isolation.

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An account of the work that is being done at the newly established Section for help to the adult deaf and deaf-blind in Brazil.

Report from Canada
Karen Fleming

A detailed report on the work which is being done in all parts of Canada, covering areas such as communication, aids, employment, living arrangements and the organization of the services.

Report from the Federal Republic of Germany
Ferdinand Zekel

A report on the German Educational Centre for the Deaf-Blind in Hanover, where 29 teachers and over a 100 resident counsellors care for and instruct 92 deaf-blind children and teenagers. In addition to this, about 50 deaf-blind adults and 30 staff members live at the centre.

Report from France
Nicole Levy

A personal account of communication difficulties and possible solutions.

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A description of the community "Kalorama", run by the Lega del Filo d'Oro, the services it provides and it's goals and aims for the future.

Reports from the Netherlands
Paul van den Berg

An account of the work and the aims of a committee consisting of people with impaired sight and hearing, established by the Dutch Union of the Blind and Partially Sighted. The group so far has about 120 members.

Jan Foks

An account of the newly formed Dutch Association of the Deaf-Blind and their relatives, Oog en Oor-Zaak, the work that is being done by the association and it's goals for the future.

Report from Norway
Karl Jacobsen, Finn Johansen, Reinholdt Robertsen, Björg Simensen

A report of a survey of the deaf-blind population that was carried out by the Association of the Norwegian Deaf-Blind. It covers areas such as contact persons, interpreters/guides, communication, social network, and mental and physical health.

Report from the Soviet Union
Marina Andrejeva

A personal account of the struggles to gain a higher education, of the problems of communication and information and the difficulties of finding suitable and meaningful work.

G. N. Bespalov and L. F. Obuhova

A dissertation on how to teach Braille to deaf-blind children with the help of various technical aids. The advantages and draw-backs of different methods are discussed.

Natalia Krylatova

The story of a deaf-blind mother establishing contact with her child; how the daughter was taught to use the manual alphabet at a very early age to communicate with her mother.

Elena Shakenova

A discussion of the different groups of deaf-blind, and their various problems regarding communication.

Leonid Shavelson

A discussion of the different considerations that have to be taken into account when services for the deaf-blind are established.

Alexander Suvorov

A personal account of the attitudes a deaf-blind person meets, the difficulties of finding adequate education and the problems of communication.

Amendment
Unfortunately this report is missing in some of the conference reports, and published separately.

Report from the Soviet Union

"How I became a mathematician", Marina Andrejeva

Till the present moment I have had no chance to address such an audience. Therefore my report might sound somewhat extraordinary to you, but I believe that you will excuse me when I say that there are three principles underlying my report: usefulness, sincerity and brevity. I beg all readers to pay special attention to what I am going to say, in order that you should be able to caution those who might find themselves in a similar position, struggling against numerous obstacles, errors and disappointments, such as I have had to face.

My hearing has grown gradually weaker since childhood, but it still allowed me to study at an ordinary school for blind children. No special arrangements were made for me, so I had to do my best to adapt to the general situation. To a certain extent that was useful, for it makes one adapt oneself to the environment.

In the meantime my hearing grew still weaker, and it became more difficult to compensate for the loss of information by using intellectual resources. In the long run the moment came when this kind of compensation was insufficient and would not work. It is but logical to suppose that this dramatic change should have resulted in a certain distortion of the picture I had of the surrounding world. I assume that this did happen, otherwise it would be difficult to explain why I failed to communicate fully with my peers and failed to make them understand me. On the other hand I started to suffer serious communicative difficulties mainly in senior classes, that is long after my intellect had already been formed. That is why, paradoxically, the information deficiency did not hinder my spiritual growth, but on the contrary stimulated it.

When I could no longer keep up communication with my comrades I focused all my attention on learning. In other words; you understand

that my zest for knowledge which astounded everybody was not only a feature of my soul, but of my soul's hunger.

I graduated from school with a gold medal award which I dare to believe I deserved. I did not however feel like continuing my education: to begin with I was tired, and secondly, I had a very vague idea of how I was going to study at an institute full of absolutely healthy and robust young people. Nevertheless I entered the mathematical department of the Moscow pedagogical Institute and my very first steps were directed at adapting myself to the new environment. It turned out even less satisfactorily than at school, for my hearing was failing me, it was to weak. By that time I had already made use of hearing aids but they were poor help. So I had the problem of finding some channel for information from, and communication with, my teachers. Very soon I discovered that the necessary technical aids were not available, and that I would have to design what I need myself. And so I did.

People tried to help me in one way or other. I was given a grant that allowed me to take on a secretary, so my mother was able to leave work and devote all her attention to me. She actually became my secretary. Unfortunately my mother did not have adequate mathematical training, so she could not receive and transmit special material to me. There was a need for additional help from competent people. I must acknowledge that my teachers and friends were very understanding about my problems; they were sympathetic and ready to help.

My deafness prevented me from hearing what was being said at lectures, so I had permission to stay away from them. I must say that we do not have enough Braille literature for higher education, so I had nothing else to do but ask my comrades to dictate lecture summaries. This they never refused to do. However there still remained the problem of how to hear the lectures. So I had the idea of making use of a device consisting of a microphone, an amplifier and head-phones. This technical "miracle" allowed me to hear the one that was dictating, but the whole process put colossal strain on my hearing and on my nerves. More often than not I had to ask for repetition. In short, all my attention was focused on registering the transmitted information. Unfortunately, I was not able to cope with this task well enough and therefore had to spend much time on correcting lecture summaries, which

on the other hand helped me to master the material simultaneously. I was always short of the necessary information, naturally, and had to strain my intuition in order to fill numbers of inevitable gaps.

As to practical sessions; in my first year at the Institute I attended them together with other students. To communicate with my teachers I made use of the aforementioned device, but as I said, the whole process was of immense difficulty, because the teachers had different voices and making out their different dictions was also a problem. Besides, in contrast to making a summary when hearing a lecture, at a practical session one should concentrate not only on receiving information by ear, but mainly on understanding it and making use of it. Oh yes indeed, it was difficult, and everybody realized it.

In spite of all the obstacles I did my best to make the people around me believe that I could master the necessary material all on my own. As a result I was also permitted to give up attending seminars. As to regular written work I fulfilled everything my comrades were supposed to do, as well as check-ups and examinations.

The major credit here goes to my mother, who followed me everywhere and served as mediator in my communication with people; the problem is that she is now the only person I can percieve with my hearing.

It would not be out of place to mention here that I think my major error lies in the fact that in my search for communication methods I basically counted on artificial compensation for my lost hearing. But on the other hand it would be true to say that this error was provoked by circumstances: where I lived no one could offer any alternative method for communication. I was only made familiar with tactile speech systems -- manual alphabet and Lorm's code, which I mastered together with my mother. But as you can understand, it was too much to ask that my friends and teachers do the same. There was nothing else for me to do than what I did. I could not foresee the tragic consequences of this practice, no one was sober enough to warn me, they were all so enthusiastic about my successes and did their best to encourage me. But my poor hearing, I did not know why, would not be inspired by this exultation, and it was crushed by the immense strain, so at the moment I can make no use of it whatsoever.

In spite of all that I managed to finish at the Institute with honours. I find myself at present, however, in a strange enough position, which is conditioned by my potentials and my real chances.

Theoretically I can see three directions of continuing on what I have already done: practical teaching, work in the field of calculative mathematics or postgraduate studies. Pedagogy – the first alternative seems the most appropriate. But where should I teach? It is clear that I would not be able to work in an ordinary secondary school for normal children since I cannot hear the children, and besides special communication devices have a very limited circulation in our country. Still I believe I can teach in a special school for deaf-blind children (there is such an institution in the Soviet Union). In the first place I could easily communicate with such children and consequently build up our relations not only on business-like principles, but on confidence too. Secondly, as far as I know the situation in this school, as regards the curricula and teaching methods, leaves much to be desired, and I flatter myself that I could make a certain contribution to bettering the situation. Thirdly, the school in question has at its disposal a number of special technical aids for teaching and caring for deaf-blind children, in particular communication devices. However, again one should admit that neither the quantity nor the quality of these facilities could be considered satisfying, which of course might hinder, or even render impossible, my working at the school.

Now, that is the reason why I have to consider my chances in computer mathematics. Moreover my turn of mind and nature disposes me in favour of individual work, rather than pedagogy. And here again I have to face the same difficulties: poor hearing, lack of a Braille display and other devices that provide for an independent and effective contact with a computer. I could work in a computer (information) centre, provided I had the devices mentioned or – and this would suit me best – work at home on a PC, carrying out orders on algorythm making and progamming.

As to postgraduate studies, at the moment I do not feel like going on with my studies. It is however well known that the appetite comes with eating, and if the work I am able to perform now, with my level of training, is no longer going to satisfy me, I would start to think of some scientific work in the area of theoretical mathematics. As to a job, I do

not have any so far. And the problem lies in the lack of necessary devices, whereas there is no lack of people ready to help.

I have done my best to convince you that what I need is reality, not illusion. I am eager to be really useful, and not only fancy that I am. As a human being I want to enjoy full rights, I want to live and not be transformed into an intellectual doll, satisfying the needs of sophisti-cated researchers and the idle public. Studying at school and at the Institute took all my powers, health and soul. For the sake of learning I denied myself the reading of fine literature, music and simple human communication. I am far from begging society to reward me. I am simply asking to be allowed and helped to realize my possibilities so that I cannot torture myself with the thought of meaningless sacrifices, sacrifices I have already made, and by the feelings of disappointment, hopelessness and doom.